

Appendix B: Responses to open-ended items

In most instances, statements by respondents have been included verbatim; however, efforts were made to correct basic grammar and spelling errors for ease of reading. The names of individuals noted in responses were removed and replaced with [NAME] to protect confidentiality. Comments followed by a number in parentheses indicate the number of people having the same comment. Each table begin with the phrase “NO RESPONSE” followed by a number to indicate the number of people who did not have anything written for that item.

Table 1. Responses to “What is your diagnosis?”

NO RESPONSE (70)
2 shattered discs
7 q-syndrome
Abdominal migraine, gerd, reflux, allergies ashma
Acetabular fracture
Acute meniere's disease
ADD-autistic
ADD-Hemophila
ADD (2)
ADD, dyslexia
ADHD (5)
ADHD /ADD /depression/anxiety disorder
ADHD, depression, hearing Impaired
ADHD, fibromyagia, growth hormone deficiency
ADHD, mild retardation, conginitive birth defect
ADHD, MMR, bipolar disorder, dyslexia, psychosis NOS;ODD
ADHD, OCD
ADHD, OCD, PTSD, depression and LD
ADHD, ODD, and PDD-NOS
ADHD, ODD, implosive depression
ADHD, post tramatic stress disorder
ADHD, severe separation anxiety, major depression
ADHD/ADD
ADHD/bi-polar
ADHD/ODD/depression
ADHD/OHI
ADHD/PTSD
ADHD; 5 bulging discs in upper and lower back
Age - ability to stand/walk for a length of time
Algheimea, heart trouble, trouble walking, trouble with hygiene and housework, memory
Alzheimers
Alzheimers (midstage)
Amputated left leg above knee
Amputee (3)
Amputee (left leg)
Amyotrophic lateral sclerosis (lou gehrigs)
Angelman's happy puppet syndrome
Anoipic encephcpaty, respiratory failure, multiple quadriplegic, surgeries, brain injury
Anxiety/bipolar disorder
Arthrietis - heart murmur - going blind - high cholestrol
Arthritis (2)

Arthritis in my spine (osteoporosis) affects right hip and leg spine
Arthritis in spine
Arthritis, thyroid, obese, fibromyalgic, depression
Arthritis, crooked spine chip
Arthritis, scoliosis, osteoporosis disc disease
Arthrogryposis (birth defect)
Arthrogryposis multiplex congenita.
Arthrogryposis (birth defect)
Arthrogryposis
Asperger, bipolar, adhd, odd
Aspergers syndrome/autism
Asperger's syndrome/bipolar disorder
Asperger Syndrome with ADHD
Asthma, heart trouble, club foot
Attention deficit/dislexic disorders
Autism - cerebral palsy - VP shunt
Autism - pervasive developmental disorder
Autism (49)
Autism and speech delay
Autism or characteristics; ADDHD
Autism PDD ADHD
Autism with pervasive developmental disorder
Autism with severe language delay
Autism, ADHD (2)
Autism, ADHD, LD
Autism, developmental delay
Autism, developmental delay, seizures, retarded
Autism, diabetic, high blood pressure, high cholesterol, depression
Autism, epilepsy, diabetes, mild MR
Autism, fragile-X
Autism, moderate mental retardation, severe speech and language impairment
Autism/ADHD/BiPolar
Autism/down syndrome
Autism/mild-moderate mental disability
Autism/PDD
Autism/Rett's syndrome
Autism: PDD-NOS
Autistic/MR
AVM, CVAs
AVM/seizure toward stroke
Back and knee pain
Back injury
Back Injury, 3rd grade level education, special education, arthritis
Back problem...it keeps getting worse all the time.
Back surgeries (four)
Back: 3/4 of my spine was redone
Bi-Polar
Bi-Polar tissue, A-typical connective, spinal pressing nerves
Bi-polar (manic-depression)/dementia, coronary artery disease, diabetic, cerebral atherosclerosis
Bilateral cleft lip and palate
Binafical
Biopolar/PTSD
Bipolar disorder (4)

Bipolar disorder, depression, anxiety
Bipolar II with psychotic features
Bipolar manic depression, schizophrenia
Bipolar, chronic schizophrenia
Bipolar, rheumatoid arthritis, fibromyalgia, disc disease
Bipolar/ADHD
Bipolar/adhd/tourette/ocd/anxiety
Bipolar/P.T.S.D.
Blind- mild learning disability
Blind
Borderline intelligence/mildly retarded
Born with cataracts but removed when young/however left blind so wear bifocals for correction, but left eye is worse.
Brain damage
Brain damage and epilepsy 1991
Brain injury (2)
Brain tumor
Brain tumor with paralysis
Braked neck - C-5 and C-6
Breakdown in muscle
Broken back
C-2, C-3, incomplete fracture of the neck
C-3, C-4 spinal cord injury, quadriplegic
C-5-6 quadriplegic
C-5 quad
C-6, C-7
C-6, C-7, quadriplegia
C-7 fracture, paraplegic
C-7 paraplegic
C.O.P.D.
C.P. (11)
C.P. and MR/DD
C/P, respiratory, chunts, spinal
C3,C7, quad
C5-6 quadriplegia; spinal cord injury.
C5 C6
C5 quadriplegic, paralyzed from chest down
c6-7 Spinal cord injury/quadruplegic
C7-8, quadriplegic
Can't walk and cannot use right hand well
Cancer
Celulites elephantites
Cerebral palsy - mild to mod. MR
Cerebral palsy (52)
Cerebral palsy and microcephaly and dyspasia, sometimes breathing problems
Cerebral palsy from viral meningitis and hydrocephalus
Cerebral palsy hypotonic
Cerebral palsy with ortho impairments, mental retardation
Cerebral palsy with severe mental retardation
Cerebral palsy, auditory processing disorder
Cerebral palsy, blind, seizures, m-r
Cerebral palsy, CVA, HBP
Cerebral palsy, moderate mental disability, developmental disability, autistic disorder
Cerebral palsy, mute

Cerebral Palsy, pervasive dev. disorder, ADHD
Cerebral palsy, seizure condition, SMR
Cerebral palsy, seizure disorder, gerd, respiratory problems, developmental delay
Cerebral palsy, seizures, brain damage
Cerebral palsy, severe retardation
Cerebral palsy, severely deaf, mentally/physically handicapped
Cerebral palsy, spastic quadraparesis, cortical blindness, optic atrophy, mental retardation, multi-handicapped
Cerebral palsy, spastic quadriplegic in type from prematurity, 28 weeks gestation.
Cerebral palsy, tourette's syndrome
Cerebral palsy, visual impairment, dev. disab.
Cerebral palsy, dystonia and obsessive compulsive disorder
Cerebral palsy/ mental retardation
Cerebral palsy/bipolar
Cerebral palsy/learning disabled
Cerebral palsy/legally blind
Cerebral palsy/quadriplegic
Cerebral palsy/seizure disorder (2)
Cerebral palsy; cortical visual impairment
Cerebral palsy; epilepsy
Cervical bulge disc, L3, L4, L5, SI bulge
Cervical cancer
CFS
Charcot-marie-tooth (CMT)
Charge association
Chemical imbalance
CHF, COPD, hepatitis C 4th stage, spinal cord injury
Child cerebral palsy, blind, mental delayed
Child needs special education
Chromosome 3P deletion
Chronic bronchitis, high blood pressure, arthritis over entire body
Cleft lip and cleft palate
Closed head injury
Closed head injury, legs - left 30%, right 20% disabled.
Closed head trauma, CP, seizures
Club feet
CMV
ColPo - oncology clinic
Colpocephaly
Complete physical disability-head injury from auto accident
Complications from diabetes, heart trouble, pressure and poor circulation
Conduct disorder/explosive disorder
Congenital amputation of left forearm
Congenital heart disease, down syndrome, seizure disorder
Congenital muscular dystrophy with trach with ventilator
Congenital muscular dystrophy/scoliosis kyphosis
Congenital myopathy, hypotonia, carnitine deficiency
Congestive heart failure, diabetic, neuropathy
Congestive heart failure, diabetes, mitral valve remover, total depression
Congestive heart failure/cardiomyopathy/diabetes
Congestive heart, hypertension, arthritis in every joint, 2 knee and hip replacement, fibromyalgia, sleep apnea.
COPD - code 496, asbestosis - code 493.9, hypertension - code 401.1, asthma - code T15.89
COPD
COPD and heart disease

COPD chronic obstructed pulmonary D.
COPD, diabetes, cholesterol, asthma, allergies, arthritis
Cornelia de Lange syndrome
Coronary heart disease, diabetes, high blood pressure
Coronary artery disease
CP with brain damage
CP, epilepsy, double asymmetric hemiplegia, legally blind, ADHD,
CP, seizure disorder
Cri-du-chat syndrome
Cripple
Crippled left leg/arthritis
Crohn's disease
Crohn's disease/ulcerative colitis
CVA
CVA at birth
Cystic fibrosis (4)
Cystic fibrosis, diabetes, seizures, muscle and nerve deterioration, vascular heart disease, osteoporosis, kidney disease
D
Dandy walker syndrome, (MR, VI, CP, epilepsy, bi-polar, brain damaged, hearing sensitive)
Deaf (6)
Deaf in left ear/slow learner
Deaf, blind
Delayed myelination (2)
Dependent MRI seizures, self-post CVA's/diabetes
Depression and ODD/uncontrollable anger
Depression, anxiety, ADHD, high blood pressure and cholesterol, remission from cancer and partial kidney failure, endometriosis, low immune system
Depression, brain injury
Depression, insomnia, anxiety disorder, panic attacks
Depression/bi-polar
Deteriorating disc
Develop delay, seizure disorder
Development disability
Developmental delay (2)
Developmental delay, cerebral palsy, epilepsy
Developmental delay, orthopedic and speech disability
Developmental delay/hyper lax ligaments
Developmental delays/cerebral palsy
Developmentally delayed-cleft palate
Developmentally delayed
Developmentally disabled
Diabetes (4)
Diabetes, arthritis, acute depression, nerve problems.
Diabetes, arthritis, and broken foot that is not properly healed.
Diabetes, heart condition, high blood pressure, etc.
Diabetes, dyslexia, injuries from an accident.
Diabetes/strokes
Diabetic
Diabetic/non insulin dep.; uses walker; degenerative arthritis/Joint; needs W.C.
Diabetic, neuropathy
Dilaha, can't read
Dementia, chronic pain, heart
Disabled, legally blind, diabetic
Distal spinal muscular atrophy

Disturbed disks in lower back
Down's syndrome with profound mental retardation
Down's syndrome, autism, pervasive mental disorder
Down syndrome - mental disability severe
Down syndrome - MMR
Down syndrome (Trisomy 21)
Downs syndrome (40)
Downs syndrome (Trisomy 21)
Downs syndrome and cerebral palsy
Downs syndrome and kidney failure
Downs syndrome m/r and scolosis
Downs syndrome partially sighted
Downs syndrome with other health problems
Downs syndrome/A V canal heart defect
Downs syndrome/ADHD
Downs syndrome/bipolar disorder
Downs syndrome/paraplegic
Downs, arthritis
Dyslexia (4)
Dyslexia and ADHD
Dyslexia, ADHD, slight tourette, OCD
Dyslexia, also ADD
Emphysema
End stage renal disease (ESRD)
Epilepsy (5)
Epilepsy (nocturnal)
Epilepsy, arthritis in right knee, right ankle, back and fingers
Epilepsy, bilateral hearing loss, cataracts in both eyes, chronic bronchitis, shoulder injury from fall
Epilepsy, seizure, bipolar
Epilepsy, syncope
Essential tremor, knee replacements, parkinsons, high blood pressure, hearing loss
Everything
Exostosis/extra bone growth which forms extra bones
FAS/ autism/ dev. delay
Fibromyalgia, lupus, OCD, depression
Fibromyalgia, sleep apnea, depression, osteoarthritis
Fragile X Syndrome
Friedreich's ataxia (4)
FX. Rt hip and femur
Genetic Eye Disease, Hearing Impaired
Global developmental delay/ Avt
Goldenhar syndrome
Goltz syndrome
Grb's palsy
Gross obesity and mild mentally handicapped (moderate perceptual impairment)
Guillain barri syndrome, HBP, cerebral palsy, anxiety, obesity and limited ambulation
Had 3 bowel surgeries from April-October 2003 - cannot lift more than 10#. Osteoporosis
Handicap (2)
Have only one eye
Haven't been diagnosed yet
HBP-PVD; Left leg amputation - RA
Head injury
Head injury (gun shot to head)

Head injury (severe)
Head injury, in wheelchair
Hearing and learning and arthritis
Hearing impaired (10)
Hearing impaired/learning delayed
Hearing impairment, no fingernails or toenails, can only see close up in right eye, small for age
Hearing loss (65%)
Hearing loss (both ears)
Heart (2)
Heart and back
Heart attack-COPD
Heart attack not much left
Heart problems/artificial leg
Heulers
Hydrocataly, spyna bifida, mielo (paralyze waist down)
High blood pressure
High blood pressure, congestine heart failure, COPD, diabetic, ospiporosis, enfizimei
High blood pressure, heart, arthritis, etc
High blood pressure; diabetes
High functioning autism
Hip replacement
Histoplasmosis
HIV / AIDS
HIV positive, poor circulation
Hopefully he will walk again and continue to get better.
Huntingtons disease
Hydrocephalus-CP
Hydrocephalus - legally blind
Hydrocephalus (S/PV-P shunt) legally blind with seizures
Hydrocephalus, cerebral palsy
Hydrocephalus/cerebral palsy/severe mental disability/epilepsy/G-Tube
Hydrocepholus - spinal bifida
Hydronephrosis
Hydrunencephulic
Hypogleamia
I'm a mentally handicap with learning cognitive
I cannot spell the diagnosis/I am in a wheelchair and cannot move from waist down.
I have a handicapped son who is profoundly192
I have back pain, and nerve damage. I have had three back surgerys.
I have quaid-spinal injury.
I want to solve the world's myopia.
I work with infants, toddlers as special instructor
Impaired sight, COPD, spinal tenosysarthritis
In remission with leukemia, hearing impaired and deaf
Incomplete C-4 acting as A C7
Joint impairment
Juvenile rheumatoid arthritis
Knee bone needs to be replaced
L-4-L-5 fusion nerve damage in left leg; 4 herniated disks in neck, need surgery; depression
Last of most good use of left hand
Learning disabled with speech. language impairments, articulation
Learning disabilities, cerebral palsy, and handicap.
Learning disability (6)

Learning disabled; arthritis
Learning problems, scoliosis, dental problems, williams syndrome
Learning/cognitive
Left hemilegia, speech impairment
Left hemiparisis, glaucoma, orthopedic disability
Left side paraplegic
Legally blind (3)
Legally blind, macular degeneration, diabetes, high blood pressure, arthritis, causing disfiguration of feet, food allergies.
Legally blind, shorttime memory disorder - brain injury
Licencephaly, microcephaly, seizure disorder, cerebral palsy
Limb-girdle muscular dystrophy (3)
Lissencephaly (2)
Lumbar-cervical disk damage
Lupus cerebritis, antiphospholipid syndrome
Lupus/MCTD
M.S.
M/M dev. delayed
Macular degeneration (no central vision, COPD, empehyza, caroded artery blockages (L60/80%)(R40-60%))
Major depression (2)
Major depression and schizophrenia
Major depressive disorder
Malformation of the brain
Manic depressive disorder/obsessive-compulsive disorder, ADHD, oppositional defiant disorder
Marfan's syndrome
MCS, fibromualgia, radiculopathy, TMJ
MD
Melas syndrome
Melkerson rosenthal syndrome, major depression, mild retardation, social phobia
Mentahyretande
Mental age- 10 years but physical age - 24 years.
Mental disability
Mental learning disorder
Mental retardation (15)
Mental retardation, C.P., spastic quadripleis, J-Tube
Mental retardation, down's syndrome
Mental retardation, major depressive disorder with self injurious behavior, C.P., Legally Blind, Stereotypic movement disorder, psoriasis, pyschosis(NOS), endentulous
Mental retardation/blindness, deafness
Mental retardations
Mental retarded, cerebral palsy, tourette, developmentally disabled
Mentally and physically disabled
Mentally challenged
Mentally retarded and seizures that are profound and severe.
Mentally retarded and speech impaired
Mentally retarded with emotional
Mentally retarded/handicapped
Methylmalonic amino acidurip (MMA), epilepsy, OCD, ADHD, autism
Methylmalonic Acidemia/Hydrocephalus with orthopedically impaired
Micro-celphaly corpus missing
Microphaly-seizure disorder
Mild cerebral palsy (2)
Mild cerebral palsy in legs
Mild cognitive disability

Mild handicap
Mild M.R. and C. P.
Mild mental disability, petite seizures
Mild mental retardation (9)
Mild mental retardation, OBS
Mild mental retardation, seizure disorder, developmental articulation
Mild mentally disable with learning disorder
Mild mentally handicapped
Mild MR, developmental delay, speech disorder, ADHD
Mild/moderate mental retardation (5)
Mild/moderate MR; speech
Mild/moderate retardation/ autistic/ multiple disabilities
Minimal change nephrotic syndrome
Mitochondrial myopathy, seizure disorder, copo, cortical deafness/blindness
Moderate
Moderate M.R., C.P., seizure disorder, spastic quadraplegia, dysphagia
Moderate M.R., severe hydrocephalus, hypothyroidism, grand mal seizures, mild C.P., VP shunt, legally blind, dependent personality disorder
Moderate mental disabilities
Moderate mental disability/behavior disorder
Moderate mental retardation (3)
Moderate mental retardation and mental illness
Moderate mental retardation/autistic
Moderate mentally handicapp
Moderate MR, cerebral palsy, spastic quadriplegia
Moderately mentally handicap
Modulaty mentally handicapp seizure disorder
Mondixide puising, left side hemi-
Mongoloid
Mood disorder NOS
Morbid obesity, bone degeneration, depression
Morbid obesity; arthritis; back surgery
Morbid obesse, osteoarthritis, high blood pressure, diabetes
Moya-Moya Disease (causes multiple hemoraghic stroke)
MR, C.P., stastic quadriplegia, severe hypertonic microasma, seizures, Gtube
MR. D.D. cerebral palsy
MR/Deaf/Phys. disabilities
MR/seizure disorder
Mulip handicap
Multi
Multiple
Multiple disabilities
Multiple disorders, prader - willi syndrome
Multiple sclerosis (13)
Multiple sclerosis, TIA's, fibromyalgia, systemic lupus, celiac sprue. Some of them started until recently diagnosed with system lupus
Murmur and scoliosis
Muscular degeneration/near blindness
Muscular dystrophy (3)
My left foot off. Please help me to get sec A. My foot cut off. Please help me. My kidney going bad and my eyes.
Myalgicencephalomyalitis/chronic fatigue syndrome/multiple chemical sensitivity disorder
Myclonia and epilypsy
Need knee surgery (bad) lung and heart condition, back problems (bad)
Neuroral migration disorder, lennox gaustart syndrome, irretractable seizures, severe profound mental retardation,

multiple abnormalities
Never been explained to me
Non paraletic idiopathic/postpolio scoliosis
None determined
Obese-very overweight
Obesity-asthama-sleep apnea
Obsessive compulsive disorder
OCD/ADHD
Osteoarthritis, congestive heart failure, hemophilia, gastroesophageal reflux disease, history bld clots, legally blind
Olivaponto cerebellar atrophy
Oppositional defiant disorder
Osteo and rheumatoid arthritis
Osteoarthritis
Osteoarthritis; rheumatoid
Osteoporosis (2)
Osteoporosis and arthritis
Over-active bladder, inactive thyroid - cancer survivor - 9 years, high blood pressure, degenerative arthritis of spine, total knee replacement
P.D.D./autism
P.V.D
Panic attacks, osteocodroma
Panic attacks, severe pain in back
Papilloma/head tumor
Paralysis chest down
Paralysis quadriplegic
Paralyzed/right leg above knee amputated
Paranoid schizophrenia and psychosis
Paranoid schizophrenia (8)
Paranoid schizophrenia, psychotic, manic-depression, bi-polar
Paranoid schizophrenic bipolar
Paraplegia, no feeling from the waist down
Paraplegia/neural deficits/spinal injury
Paraplegic - level T2-T3
Paraplegic (7)
Paraplegic C4-C5
Paraplegic T11 and T12
Paraplegic wheelchair
Paraplegic, dwarf
Paraplegic, quadriplegic
Partial quadriplegia
PDD and sensory integration disorder
PDD/fine motor impaired
Pelizaeus meuzbacher (3)
People who have limited abilities need financial help, housing, and transportation and medical assistance which I do not have
Perisylvian syndrome, digeorge syndrome
Permanent disability - progressive "partial quad"
Permanent quadriplegic, bedridden, and scoliosis
Pervasive developmental disorder
Peter's anomaly plus with short limb dwarfism
Pharyngitis, squint, legs calves peroneus, hypothyroidism
Physical disability/back problem
Pinch nerve in neck, carpal tunnel in both hands, retentive cuff.
Plagiocephaly, torticollis of the neck, left sided hemifacial microsomia, Major speech problems

PMG, autism, hypotonia, seizures, ulcers
Polio - 1951
Polio - post polio
Polio (4)
Polio, diabetes
Post-polio syndrome (9)
Post depression and HIV
Post encephalitis
Post polio - stiff left leg
Post polio due to severe pain from head injury
Post polio syndrome and degenerative disk disease of neck and lumbar, fractured vert #16 years ago
Post polio syndrome (PPS) sequela
Post polio syndrome,diabetic
Post polio, diabetic, osteoarthritis
PPD
PPD, NOS (2)
Prader-Willi syndrome
Problems with legs and feet
Profound M R, C.P., seizures, osteoporosis, kyphosis, scoliosis, hiafalhernia, gerd
Profound M.R., C.P., seizure disorder, legally blind, GERD, gastrotomy tube
Profound M.R., down syndrome, legally blind, hearing Loss, endentulous
Profound M.R., legally blind, osteoparosis, focal and myoclonic seizures, scoliosis, kyphosis, spastic quadriplegia, nystagmas
Profound M.R., seizure disorder, behavior disorder with SIBS, Gtube for meals, Stradisms, Kyphosis
Profound mentally retarded
Profound MR, CP, dycphagia, spastic Qu., Sx disorder.
Profound MR, hydrocephly, congenital cerebral maldevelopment
Profound MR, rubella syndrome, Sx disorder, microcephaly
Profound MR, spastic quadriplegia, microcephely, severe scoliosis, multiple infractures, hastontomy tube, etc.
Profound retardation
Profumi mental illness
Pyschosis, major depression, anxiety disorder
Quad-spinal cord injury
Quad - neurofidromatosis
Quad C-45
Quadapledic C-3
Quadruplic spinal
Quadrappedgic (Paralized from neck down)
Quadruplic - C5 - C6, chronic pain
Quadruplic (21)
Quadreplegic- 1 kidney, diabetic
Quadriplegia at C6/7 level
Quadriplegia level of T4
Quadriplegia/spinal cord injury
Quadriplegic C5 and T7
Quadriplegic SCI
Quadriplegic: paralysis from chest down.
Quadruplic C5 broke
R-A
Restless legs syndrome
Retardation, venus stasis, digestive problems
Retarded
Retinitis pigmentosa
Retinitis pigmentosa and hereditary and autonomic nerve syndrome

Rheumatoid arthritis (3)
Right foot has been amputated
Right leg cut off
S/P CVA, fractured femur
Sacoidosis of central nervous system
Schizoffective-depressed
Schizoffective
Schizophrenia
Schizophoemia paranord type - learning disability
Schizophrenia (13)
Schizophrenia, bi-polar
Schizophrenia, bipolar mixed, social anxiety disorder, general anxiety disorder, mixed head syndrome
Schizophrenia, rheumaroid arthritis
Scholis (I have a Rod in my back)
SCI and TBI
Scleroderma
Scoliosis-curvedure of the spine
Scoliosis,cerebral palsy,asthma,developmental delay,epilepsy
Seckel syndrome (2)
Seizure disorder (3)
Seizure disorder/delayed development/severe-profound
Seizure, asthma
Seizure, bronchitis, headpains, bad memory
Seizures, physical handicapped
Self-back and digestion disorders; muscular dystrophy
Severe brain damage
Severe bronchitis; severe skeletal disorder; malchromolis-both knees
Severe CP microcephaly
Severe epilepsy and lower extremity severe atrophy-progressive
Severe mental (2)
Severe mental retardation
Severe mentally delayed
Severe MR, ADHD, ODD
Severe rheumatoid arthritis
Severe spastic quadridgeplegic, cerebral palsy, blind, nonverbal, severe mental, motor and fine motor delays, 100% totally depends on others. Wears diapers with general health guarded. Feed through a tube, wears diapers.
Severe spina bifida
Shaken baby syndrome
Short term memory loss
Sinus and throat cancer/manic depression
Sjogrens syndrome/CIDP, hypoglycemia, anemia, osteoprosis, esophageous spasms, MPV, arthritis, trick fingers on both hands
Skitzaraniz
SLD, hearing Impaired, 504 disabilities
Slight mental retarded
Slow learner, born with back problems
Slow learning (2)
Slow learning/bad hearing
SMA=MD, spinal muscular
Social anxiety disorder/schizophrenic
Soto's syndrome
Spastic quad., seizure disorder, blind
Speech problems
Spina bifada/mild mental retardation

Spina bifida (18)
Spina bifida and arnold chiani malformation
Spina bifida and mild mental D.S.
Spina bifida, arnold chair malformation, seizures D/O
Spina bifida/hydrocefilis
Spina bifida/hydrocephahoas/CP/MR
Spinabifida, hydrocephalus, respiratory distress, seizure disorder, asthma
Spinal and head trauma
Spinal cord and head injury; can't talk or walk
Spinal cord injury (5)
Spinal cord injury; paraplegic
Spinal muscular atrophy (3)
Spinal muscular atrophy and beginnings of respiratory failure
Spinal muscular atrophy type 2
Spinal muscular atrophy, a form of muscular dystrophy
Spinal stenois
Stroke-speech and right arm and leg
Stroke - spinocere bellar
Stroke (8)
Stroke (right side)
Stroke affecting left side, spinal and closed head injury
Stroke and enlarged heart
Stroke and total left knee replacement and grandson was in a car accident, has learning and mental problems
Stroke, chf, diabetes, pvd, hypertension, incontenent
Sugar
Systemic lupus/clinal depression, incontinence
TBI
TBI, paralysis
TBI, Quad-P
Tetrology of fallot heart problem
Thyroid cancer
Total impairment; lower back
Total left hip replacement
Totally disabled,disc herniation at L5-51,failed fusion at L5-51,screws and rods at L5-51andL3-4,and posterolatenhecal sac stenosis L3-4 and L4-5
Tourette's syndrome (2)
Tourette's syndrome, ADHD, ODD, M-RTD
Traumatic brain injury (5)
Traumatic brain injury (MVA)
Traumatic brain injury/quadraplegic
Traumatic head injury and stroke
Travis - spina bidea/sheena - mental handicap
Triple by-pass,Rt CVA with both Rt and Lt hemisphere dysfunction□
Trisomy 18
Trisomy one Q and duplicate
Tuberous sclerosis
Type1 diabetes; asperger's syndrome
Unbalanced translocation - partial monosomy chromosome 40, partial trisomy chromosome 13
Unknown muscular disorder scoliosis etc.
Ushers syndrome
Ushers Syndrome
Variety of diagnoses
Vascular problems, end-stage penal disease, congestive heart failure
Vision impaired and moderate mental case

Visually impaired and weight impairment
Visually impaired/mentally retarded
Warkany syndrome (Trisomy 8 mosaic)
Was born early
Williams syndrome
Wolf parkin sonwhite, mitral, aeortic segurgitation stroke

Table 2. “Other” Type of School or Program Enrolled In

NO RESPONSE (1,009)
Adult literacy
Allen New Hope Center
Alternative
ARC
BARC; sheltered employment.
CARC (3)
Classes at UL
Community Opportunities in Ascension
Computer classes
Cooking school
DAARC Activity Center
DAARC supported employment program
Day habilitation program. (3)
Daycare in home
Daycare/preschool
Donaldsonville Association of Retarded children and council of aging.
Early Steps
EIP
Elementary School for Emotionally Disturbed-Alternative
Employment services provider
Evangeline ARC Day Program
Foster care
GED program
Group Home Center
Handicapped School
Home bound (4)
Home teacher 2x week
Hospital /Homebound
Job skills training at NAMI Friendship Club
LA school for the deaf
LCDC
Louisiana Special Education Center
Magnolia School Work program
Masters Degree
Morning, noon, [illegible] learning situation.
NAMI (12)
New Horizon (MLSE Program)
None
Online University through Internet
Preschool

Prevocational Sheltered Workshop (9)
Psycho-social
Residential facility
School for disabled
School for the deaf and blind
School for the visually Impaired
School of disability—ARC
Self-directed
Shreveport, Bossier Adult Academy Renewal
SLIC Computer Training
Special Autism Class
Special instruction at home
Speech-early intervention program
SSD#1
Supported employment
Therapy
Ticket to work
Vita
Voc-Rehab
Vocational Day Program
Vocational sheltered workshop
W.I.N.
Winn Dixie bagger through ARC
Working at Beuregard Arc

Table 3. “Other” Problems Finding Work

NO RESPONSE (858)
100% disabled.
A job that is suited for someone with my disability.
Afraid to work, I have no memory.
After age 22 and highschool certificate, we are forgotten.
Age (too young) (24)
Awaiting LRS support.
Because of my medication I sleep most of the day.
Being a mother of a disabled child, I need to give him more attention. There is not enough time.
Brain damaged.
Can't get a job because I can't drive.
Can't tolerate pain.
Can't walk due to my shoulder.
Can't walk most of the time.
Can't walk or talk.
Can never be employed.
Can only get job if consuling is taken at the same time.
Cannot bend, stoop, reach up or down or look to my left.
Cannot drive school bus with current disability.
Cannot drive. (2)
Cannot find a job I can work.
Cannot make make enough money to cover debts that ocured while being sick, so I'm going to college to get a degree to be able to get a job with a good pay.
Cannot talk.
Cannot use hands.

Cannot work due to child's disability.
Cannot work long hours and still in school.
Child cannot speak or communicate.
Client is unable to work.
Cognitive and physical delays; need full time job coach.
Cognitive disabilities, mental health issues, need full time coach or staff.
Cognitive limitations (2)
Confined to a wheel chair and need assistance.
Cut state aid.
Dependent on another person to take care of my needs.
Depression.
Disability (14)
Do not know yet.
Does not apply.
Does not know how to speak up and communicate.
Don't know or not trained to do anything and health.
Don't know where to go for help.
Don't know where to start.
Don't own a car.
Don't understand enough to work.
Falling asleep walking stand concentration.
Few marketable skills.
Finding work with my disabilities which pays enough.
Forgetfulness.
Handicapped.
Have not looked.
Haven't had training yet.
His society anxiety disorder.
Homemaker.
I'm not willing to pay bankers debt.
I'm on disability S.S.
I am not looking right now.
I am not seeking employment.
I am unable to leave my disabled son because of medical reasons.
I can't sit for more than 15-20 minutes.
I cannot use my arms, hands or legs.
I do not know, I am still in high school.
I do not work. I go to school.
I don't know what the problem is.
I have a disabled child to take care of.
I have a handicapped daughter whom I have to take care of.
I have a small child.
I have lumps.
I want to be able to be on a job without help.
I would need staff assistance, especially for personal care.
In severe pain everyday.
Lack of medications.
Lack of understanding, condition is not visible.
Laws regarding disabilities.
Learning disabled.
Little information.
LRS need to educate the community about H.I.
Medical problems.

Medicine prohibits a lot of jobs.
Mental condition.
My perceptual impairment and my obesity.
Need full time job coach.
Need help looking.
Need home job.
Need job coach.
Need one on one training.
Need permanent job coach.
Need staff, difficult to find employment with my type disability.
Need surgery.
Needs constant help
No child care.
No help finding jobs.
No jobs in my area accomodated by my disability.
No jobs in the area I live in, need help at all times.
No jobs with personal supervision.
No opportunity.
No wheelchair.
Not enough acceptance to help train him with the basics to begin with the basics of life. No one will give him the chance that he needs.
Not enough money.
Not having the ability to adjust.
Not many opportunities in my area.
Not mentally or physically capable.
Not seeking employment.
Not trained.
Not willing to train.
Nothing local.
Only able to do secretarial.
Pass test.
People do not understand building projects, air fresheners, perfumes make me sick.
People don't pay for transportation for the disabled such as gas or car expenses.
Physical and age related issues.
Physical condition does not permit long hours.
Physical disabilities (5)
Quadraplegic and totally bedridden on alternating air pressure mattresses.
Raising an 11 yr. old son, need to be available for him.
Reading/writing skill level.
Requires one-on-one supervision to stay on task.
Retired (12)
Semi-bedridden.
Severe social impairment.
Severe stroke.
Short attention span-need supervision.
Short attention span.
Small town, not enough suitable jobs.
Speech
Still under doctors care.
Stroke in eye/migraine headache.
Student (15)
Their funding.
There are not hiring good people.
They will cut my benifits.

Tolerance.
Too cold, uncontrolled diabetes and blind.
Trained staff.
Transportation to learn skills I can do.
Unable to work (34)
Very limited training or jobs available for persons with severe physical disabilities.
Weigh ability to lift.
When my daughter is sick on top of her disability, I have to be there.
Will need medicaid waiver for personal care attendant.
Would lose medical benefits.
Would need an assisted workplace.
Would need in home training.

Table 4. “Other” Methods of Transportation Used

NO RESPONSE (984)
Agency bus
Ambulance (8)
Arc of Iberia Shuttle.
Arthritis.
BARC picks me up for work.
Bicycle (6)
Bicycle or airplane.
Bossier Parish Community College van transportation
Bus for school or parent car.
Caretaker
Church van
COA (2)
D.A.V. van.
DAARC picks me up to attend the program.
DAARC transports me to the center.
Electric wheelchair.
Facility transportation (14)
Family member's car (7)
Family member (4)
Friends, neighbors, church members help often as possible but most work and many times I have had to cancel doctor appointments due to lack of transportation.
Group Home transportation. (4)
H/C van.
Handicap acc. van other person has to drive.
Hitchhike.
Hospital Vans.
Husband's truck and sister's truck.
I am too sick to leave my home - I need in-home services.
I have a van with wheelchair lift, I do not drive.
I have no other transportation access.
I pay someone to take me to the doctor.
Lafourche COA.
Lift for van.
Magnolia School Transportation.
Medical transportation when available.
MIT Transportation

My grandparents bought a customized van with lift for me.
My mom has a van but no lift on it.
Need driver at all times for personal van.
Need van with wheelchair lift.
None yet.
OCS.
PCA's (9)
PCA worker 15 hours a week.
Pickup truck-have to put up 2 boards and drive wheelchair up.
Powerchair for local store/PO.
Program.
Rebecca does not drive.
Residential transportation. (2)
School bus (4)
School bus with lift for school transportation.
Shuttle Bus and staff.
Special education school bus.
Sportran Lift Line is unavailable due to schedule overload when needed for work schedule in AM and PM. Not enough people or equipment.
Staff what care for me.
Staff.
State facility transportation.
The group home provides transportation.
The group home van where I live.
Van (2)
Van on campus.
Van with lift. (3)
We have purchased a used wheelchair lift van. That does not meet the needs of my husband. He barely fits and it runs terrible.

Table 5. "Other" Problems with Transportation

NO RESPONSE (951)
Acadian is most always late and my baby sees specialists at Tulane and Children's Hospitals in New Orleans. Lots of problems! Need help acquiring a modified vehicle (reliable) for transports.
Access.
Adam lives in a rural area. He can drive but has little experience in heavy traffic.
Afraid to ride in cars after accident.
Agency bus.
An aid is needed.
Aside from my parents, there is none as I live in a poor, rural parish.
Can't afford insurance to be able to drive.
Can't afford it.
Can't drive, depends on mother.
Can't pass the eye test to receive a drivers license.
Can't pay notes.
Can't read so it is hard for him to travel alone.
Cannot drive due to Autism (Asperger's). This condition also hinders his diabetes self-care.
Cannot drive. (4)
Cannot get me to church and some social activities.
Cannot go out with electric wheelchair.
Cost of insurance.
Costs expensive.

Cut backs cause great inconveniences; i.e. he has to ride early to appointment and stay all day even after finished.
Depends on family.
Difficulty remaining in seat while mom is driving.
Do not have a car.
Do not have lift for wheelchair.
Do not know how to get any other transportation other than walk of family.
Does not drive. (2)
Don't have way to transport wheelchair.
Don't like traveling far distances.
Don't qualify for transportation services.
Don't want to depend on too many people.
Drivers are not trained to work with people with disabilities
Drivers.
Employers don't want me if I use public transportation. They consider it unreliable.
Expensive gas prices increase.
Family must provide a van modified and wheelchair lift and raised roof and if it doesn't work there is no back-up.
Family needs a van.
Finding people to drive me.
Gas prices very high - not able to afford, also uses buses.
Going to loose our vehicle because of bankruptcy.
Got to find a driver.
Hard to get in and out.
Have to have help to go anywhere.
I am too sick to leave my home. I need in-home services.
I am unable to afford changes to my vehicle that would allow me to continue to drive myself in the future.
I cannot afford to buy my own vehicle.
I don't have a license yet.
I have a hard time walking wherever I go.
I have to depend on disabled parent.
I have trouble paying car note.
I just need a car.
I need a driver.
I need a handicap van.
I need a lift and training on how I would use public transportation.
I need a longer lift van.
I need full assistance and a lift. (2)
I need longer van.
I need personal care attendant and lift.
I need someone to get my wheelchair in and out for me.
I need someone to help me and a special lift.
I need staff with me and a lift.
I need wheelchair accessibility.
I work under contract with the Office of Mental Health. I park downtown and my provider doesn't pay for parking or my transportation to another job site.
If I need to get to New Orleans for appointments., if there are no others going then transportation won't take me.
If my van breaks down, I have no transportation.
Illness.
It can be difficult to arrange.
Late or no show.
Left up to the group home where we go.
Limited funds and old cars.
Live in rural area, do not drive, family car needs repairs
Load/unload into minivan, also walk into/from house. Even with assistance it is very hard for mom up and down 3 steps high into van.

Maintainence.
MITS has limited times and you have to call a week in advance.
Mom and dad are not able to take me because of their age. They are disabled.
Must have a driver for my own vehicle.
Must have driver for my own vehicle.
My car is broken.
My mom and brother work.
My mother and father work and they have to get me to and from work also.
My mother works and it's hard for her to push me around in a manual workout wheelchair.
Need a car.
Need a lift to help me transport and use my scooter, Ele, chair.
Need access to get wheelchair lift for van.
Need assistance and lift.
Need full assistance to use a vehicle.
Need larger vehicle.
Need lift for van for wheelchair.
Need my husband to take me where I need to go.
Need someone to drive and ride with me.
Need someone to drive me and I have to pay that person.
Need someone to lift.
Need special vehicle to drive.
Need van with wheelchair lift. (2)
Need wheelchair lift. (2)
Needs someone to drive for her.
Never really tried to find alternate modes of transportation.
No a/c or heat.
No gas.
No license. (2)
No medical transport vans w/ lifts and difficult finding services for medicaid.
No one else offers or Louisiana transit only will take him for all day outings- no one to tend to his needs and he can't do it himself.
No reliable car. Old driver, no one else lives with us.
No transportation in our area.
No way to take my powerchair. I have to leave it at work.
Not always available; live in rural area.
Not available in ascension parish.
Not available.
Not enough handicap parkings at malls and busy shopping centers.
Nothing available.
Only by ambulance.
Only when family provides.
Other than me, no daycare or other would have transportation for a wheelchair.
Other than my parents who are old, it's not available.
Public transportation isn't available here.
Pying insurance.
Require qualified supervision.
Severe pain keeps me from driving.
She has to work.
Should not be driving.
Someone has to be home to drive me.
Sometimes I need someone to drive me around.
Sportran lift line is unavailable due to schedule overload.
The cost of maintenance and insurance. No services add this to your living expense to qualify for services, but you have to have them by law.

The van we have has no lift and I weigh as much as my mom and she has to put me in and out of the van.
They need a bus system in Iberia parish just like Lafayette does so people without transportation can get to and from one place to another.
Too low for me to sit up straight.
Transported by parent.
Trouble ambulating to and from.
Unable to afford wheelchair accessible van.
Unable to drive anymore.
Unable to travel alone.
Van accessibility.
Van needs to be available and well maintained.
Waiting lists.
We have to pick him up out of the chair and put him in the truck and also drive the wheelchair up on the back of the truck.
Weather interferes with bike riding. (2)
When I tried using it.
When vehicle is in repair shop I ride bus system.
Won't know until [NAME] is an adult.

Table 6. “Other” Thing Needed to Live Independently

NO RESPONSE (951)
24 hour care.
24 hour supervision, respite care, etc.
24 hour supervision.
A car and more money
A good paying job.
A miracle.
A much longer house for my wheelchair.
A place I can afford.
A place that allows pets.
A section 8 voucher to move.
A suitable group home - they are hard to come by - waiting list is 7 yrs long
A trade/funds.
Access to medical, social, etc. connections in the community.
Affordable house (2)
Approval for our family because they say we make too much money.
Assistance in daily care plan, someone helping daily with my care and financial assistance also.
Assistance therapy.
Assistance with rent or mortgage.
At this time, no where.
Be back on my meds.
Better house.
Bus line.
Cannot live alone.
Capital.
Car
Care
Case manager.
Case worker who is reliable.
Complete care.
Daily nursing care, specialty staff.

Don't know...more money.
Driver's license - job.
Driver's license, job,car.
Driving lessons/approval for driver's license due to blindness.
Dwelling built for people with MCS.
Dyslexia program in public school system used appropriately to educate dyslexic needs (a bulletin 1903 program)
Electric wheelchair. (2)
Ending an affordable place to live.
Enough money to cover cost of living.
Financial assistance (28)
Fix up or move.
Full time staff.
Handicap van.
He is still in need of modifications, but his medicaid waiver life time cap of 3,000 dollars is already all gone and he can't afford any modifications and neither can his fiance who is a single mother of two children. He has no family of his own left.
Help to shop, clean, cook, and handle money.
Help with managing finances.
Help with normal home activities.
Help with shopping and managing money.
Helps parents.
Higher pay.
Home help.
Home.
I am a student.
I am married and my wife takes care of my needs. Without her I would be unable to live alone.
I have a mobile home.
I have two kids ages are 6 and 10. I need help with them.
I would like to own my own house, but can't afford it.
In an apartment.
Income that has no major effect on government assistance.
Independent living skills.
Job (3)
Job for income.
Larger home.
Life chair.
Living skills training-someone to check on me.
Longer home.
Lower rental price.
May need supervision.
Medicaid
Money and transportation.
Money for down payment.
Money to buy a house.
Money to purchase.
More help; shorter waiting lists.
More income-fewer medical expenses.
More income to relocate.
More training.
Need first time home buyers program like for disable people who is on a fixed income something to rent to own.
Nursing services in order to keep son out of institution care.
One-on-one trained staff.
One on one supervision on a daily basis

Other housing options.
Own apartment or house.
Own house. (2)
Part financial help with rent.
Pay this off and remodel.
Reliable workers for non waiver.
Respite or center.
Safe, decent, affordable housing.
Section 8 voucher for mom and need to go to another neighbourhood.
Section 8 voucher where I can get an apartment or house on a busline.
Security devices.
Shower stall needed at least not having to lift/pull legs over top of tub.
Some struggle attendant.
Someone to check on him and guide him in learning daily basic functions (can work from a checklist well).
Someone to watch over 24 hours a day, seven days a week.
Structured plan with daily check-in, drug test and mental health care.
Supervision (3)
Teach me something to occupy my time; transportation.
To move.
Transportation (7)
Transportation with a wheelchair lift.
Unable to take medications cook, personal care, and had to give up apartment 2 1/2 yrs ago
Vehicle such as small mini van-electric wheel chair scooter lift-counseling.
Voucher
We probably need a bigger home. The present home is too small; my husband is confined to 3 rooms.
With family.
With training.

Table 7. “Other” Barrier to Social Life

NO RESPONSE (657)
100% disability
A child with disabilities.
Acceptance from others
Activities are not accessible.
Age (11)
Allergies.
Always goes to so many places by herself: cause sister who is a year younger treats her mean sometimes (at home.)
Ambulation problems.
Anxiety-social skills
Anxiety
Appropriate social behaviors
Attendants are not always available to assist in transporting or providing care.
Autism-social skills difficulties
Autism and trained staffing
Availability of friends/family-assistance (not enough).
Available information, activity schedules, and consistency.
Baby is house bound. Cannot be around other kids who are sick-trach and G-tube, 15 hour feeding pump.
Because of my sickness (MS)
Becoming bankrupt.
Bed bound.
Behavior affects ability to stay in public places

Behavior disorder
Behavioral concerns.
Behaviors and looks by others.
Being a student.
Being able to have my own place.
Being alone
Being disabled.
Being single
Both corners of a city block need down ramps. City hall needs a bigger elevator.
Brain injury alienates people.
Breathing treatments, lung prep.
Can't afford it
Can't deal with the public.
Can't get a wheelchair that I can go outside with.
Can't get around by myself
Can't get up out of bed; need someone to dress me
Can hardly walk.
Can not go over to a friends house without the aid of my parent.
Can not walk or talk.
Cannot afford to do much.
Cannot do his own driving
Cannot go unless assisted by family member
Cannot talk.
Cannot walk , speech problems.
Cannot walk or talk
Chronic back pain.
Cognitive/Communication limitations.
Comatose.
Communication
Communication access, interpreters or captcomint are not readily available.
Communication barriers.
Communication limitations
Connections other than family
Cost of gas.
Developing and age.
Developmental age (developmental disabilities)
Disability (60)
Disappointed with people
Do not feel able to get up and do things
Do not have enough energy; get tired too easily.
Do not like crowds.
Do not like people
Do not want to visit others
Does not apply.
Does not like to be around noise or people
Does not socialize well with others.
Does not speak.
Doesn't know how to interact socially
Doesn't like to be with other people like me
Doesn't meet her needs
Doesn't want to
Doesn't want to leave mother.
Doing regular therapy

Don't belong
Don't feel like getting out.
Don't feel well enough to.
Don't get along with others.
Don't know of any activities for the disabled. Would like to know.
Don't know what is available.
Don't want to go alone.
Electric wheelchair
Enough funds.
Excessive nerve pain
Extreme physical limitations.
Family and friends don't have time to spend with us
Family members don't have time.
Family needs a van/illness
Fatigue
Few friends, money
Few opportunities to meet people
Financial
Financial limitations, but overall, he has an active social life with friends
Friend member substance abuse, mental domestic marriage problems
Friends' home not accessible
Friends
Friends don't have time.
Friends schedules are different than mine
Friends too far away/illness/bad weather
Gas money.
Get tired very fast
Grandma too old to know or take me - can't see well at night.
Handicap parking too limited
Hardtime understanding.
Has a hard time dealing with stimuli
Has problems making friends.
Has to be accompanied on any outings
Has very active social life.
Have no problem
Have to attend to my daughter.
Have to have a motorized lift
Having 2 little sons 3 and 5
Having to work for insurance.
He is as social as he wants to be.
Heeding honest friends.
Home bound
Home health house arrest
Home improvements.
I'm always sick, I get tired easy, I have no money
I'm not able to clearly identify my peers.
I'm not getting to plan my own activities.
I'm on Hospice, I'm home bound
I'm satisfied with my social life.
I am a quadriplegic.
I am having trouble finding friends that is on my level. Most friends are below my level. Nothing in common.
I am involved in a lot of social life.
I am too sick from a severe illness.

I can't do anything without help! My father is 75 and disabled. My primary caregiver (Stepmom) also has some health problems.
I can't leave my husband alone
I can't walk w/o pain, but have no WC to get out more if it was possible when I do get out for a while. I will be laid up for the next 4 to 5 days in pain.
I cannot get out and go to friends and family homes because everyone don't have handicap ramps.
I don't always want to go out.
I don't care about activities other than my job.
I don't like socializing.
I feel depressed/OCD and don't want to be around people
I feel like I do not fit in anywhere. I always feel in the way.
I have no one to call a friend, no one cares to learn sign language
I have to depend on my family.
I have to depend on only my sister for any social activity.
I have trouble sitting for long period of time.
I live in a rural area.
I live with my mother, she worked 2 jobs and she is too tired for social life.
I need a job.
I need a scooter chair to get about. I can't stand for a long period of time. I can't walk very far, sometimes not short distance either.
I need assisting.
I need personal care attendants to dress and get up. The programs provided do not pay enough to get dependable help.
I need something to help me get around; I cannot walk.
I need to be able to go out whenever and close to and have my communication will using WC.
I often find we are unable to attend theaters, sporting events, etc with family or friends as a group (only 1 person seated with disabled)
I shake too much.
I stay depressed all the time.
If I had a lift for my auto so I could use my scooter to transport me.
Illness- being afraid.
In a nursing home.
Inability to communicate and have strangers understand me
Incapable
Incarcerated
It's even hard to go to church as a family- fiance is also disabled and we can't keep a worker in the home, all they want to do "sit" for the EDA waiver services.
It's hard for my mom to take me.
It is difficult for our family to handle her physical needs.
It is only mom, dad or one of 4 siblings who can give him the attention, play, socialization he needs; he recently got a PCA worker again
Kids don't play with me because I'm different
Lack of energy.
Lack of proper medication
Lack of socialization
Like to be alone.
Limit friends and family.
Limitations due to poor health
Limited opportunities
Limited speech and social skills.
Live in rural area, need more friends
Lives with a child with a disability
Loud noises.
Low self esteem, no get up and go, tried all the time
Low self esteem.

Mainly having to get around.
Meeting others with similar disabilities
Memory.
Minor
Money (29)
Money and my own reliable transportation
More money needed and more friends.
More public restrooms.
Most people his age do not associate with him
Movie theater not captioned
My daughter sits at home all day; is on waiting list for a day program but there is not enough funding
My disability - communication skills
My father don't have enough income to afford many social activities.
My sociability.
My son doesn't walk and talk
My vision is limited and I need someone to take me places.
Need 24 hour assistance.
Need a wheelchair and fixed to handle it in my car.
Need assistance and health concerns prevent me from going out in inclement weather.
Need assistance to go places, have to use a cane, can't open doors, shop without support.
Need assistance with friendships.
Need assistant at all times to do things I'd like to do.
Need constant assistance
Need dependable trustworthy person or group to accompany.
Need full assistance and support
need full assistance at all times
Need full assistance to go out into the community.
Need help to get me there and help me.
Need help when going places.
Need PCA-don't know to get one.
Need someone with me at all times.
Need special skill
Need to work. Need money to care.
Need wheelchair.
Needs a PCA to drive and take her to places
Neurological bowel and bladder problems
Never accepted by society.
No-cognitive behavior.
No activities or ARC in my parish or within 20 mi, I seizure every 20 minutes and people are fearful
No driver or the weather.
No interesting places.
No interpreter for my understanding.
No job opportunity
No job, no money.
No lift in van
No motorized wheelchair
No people of my age with my disability or people not accepting of my disability
No qualified respite
No reliable wheelchair
No rental home of my own
No services available at this time.
No way to use wheelchair.
Nobody other than my mom to take me and do things with me.

Normal peers don't include after school disabled peers are limited
Not able to get around. (2)
Not accepted by peers
Not adjusted to this new life style yet
Not always funds to go
Not aware of programs.
Not being able to blend with society
Not being able to drive; food and snack requirements for diabetes.
Not being able to have my own car and visit alone
Not being able to work and pay my bills and going back and forth to the doctor. Always in pain.
Not enough accessible bathrooms
Not enough events for people like me.
Not enough help (2)
Not enough opportunities
Not enough programs for handicap children.
Not enough things geared toward children with disabilities - ex: sports
Not enough things to do
Not enough time. (3)
Not having my own house and my own car
Not interested (2)
Not interested in being in public or with others.
Not interested in going any where
Not knowing how to communicate well.
Not many community activities
Not many want to play with me, not invited to parties. I have 1 good friend and he's 4 years younger
Not old enough to have social life out of home.
Not the right friends.
Not very social.
Nothing goes on here
Nothing really.
Obesity and not able to get around.
OK as is.
Our car
Outbursts and aggressiveness
Pain dealing with disease.
Parking difficult
People acceptance.
People don't understand my disability.
People his own age with disabilities.
People judge me before they know me cause of disabilities
People to go with - places to go.
Perceptual impairment.
Personal problems
Personality conflicts
Physical disability (4)
Physical limitations, such as dancing, alcohol, etc.
Poor interpersonal skills
Problems communicating.
Problems with illness and money.
Public transit bus.
Reflux/chronic asthma
Rejection by public-No PCA-No companion
Safe place to go.

Satisfied.
School work
She can't take care of herself
She is getting heavy - loading her up and wheelchair. I feel like my back is going to break. Rainy days no cover by the time you get chair and (name) out everyone is wet.
Shy
Shy and don't communicate much.
Smells - perfume/aftershave mostly, candles, air fresheners, pesticides, moldy mildew smell.
Smoke and shortness of breath
Social behavior problems
Social problems.
Socially inappropriate behavior.
Some are not safe
Some stores have aisles too small for a wheelchair.
Sound sensitivity and acceptance
Spend as much time as behavior will allow
Still in pull-ups, messy eater, difficult to stay still
Stroke
Structure of building doesn't conform for wheelchair
Suffering with my back and I can't walk far. I need an electric wheelchair
Teenagers do not understand blindness.
The inability to communicate.
Therapy after school too tired. Also too far away.
There is not enough programs for these young adults.
Time (3)
Time and money
Time, illness, weather
Too difficult to move around.
Too hard to get around physically.
Too quiet or shy
Too shy timid (social disorder)
Too sick.
Too tired and in too much pain after work
Too young (3)
Total depression
Transportation not reliable
Trouble walking and no memory.
Unable to get out of bed at present time
Unable to speak.
Unable to walk or stand long.
Unable.
Very hard to transition and to be in public places
Very immature for her age
Walking and stairs.
Walking tires me out.
Walking.
Weather
When my seizures come on.
With family all the time.
Without a way to transport my powerchair, I cannot go out.
Work and school
Work hours
Would like to be more involved in after school activities at school; appropriateness and acceptability

Table 8. “Other” Barrier to Attending Place of Worship

NO RESPONSE (810)
Acceptance
Again, too hard to get around physically
Age
Allergies and breathing
Always worry about bills and not being able to take care of my family.
Ambulance
Anxiety-social skills
Anxiety
Attention span
Bad weather when getting in and out of the car
Because of my sickness (MS)
Bed confined
Bedridden
Behavior (5)
Behavioral
Behavioral concerns
Behaviorial problems
Being too active/not doing well in confined structured activities
Besides the buildings not being accessible and not enough transportation, other members are not allowing me (blocking me) - no joking.
Can't go and can't walk good - our church comes to our house and gives us Communion
Can't go to church no one to tend to my daughter.
Can't sit too long or stand too long
Can not sit in low seat
Cannot go anywhere without lift to get into the van
Cannot sit very long
Cannot take loud noises.
Care givers
Caretaker does not feel like getting ready all the time, she is handicap also
Childcare
Close supervision
Clothes
Comatose and not the right transportation
Cost of gas.
Crowding and wheelchair access.
Deaf
Depending on others
Depends on the weather
Depressed
Depression
Disability (11)
Do not attend
Do not have my own lift van so I cannot go when I want or where I want.
Does not know what it all means
Does not like noise or be around people
Doesn't understand
Don't have time.
Don't like loud noise
Dr. visit and school takes up most of my time
Drain all the time, no get up and go, sad, lonely, depressed

Electric wheelchair
Emotional problems in crowds, grand mal seizures, sensitive to crowd noises
Family does not always go
Family doesn't attend
Fatigue
Forgetfulness.
Gas costs too much.
Get tired or just not feeling well
Hard for me to get up and down steps.
Have to catch rides with other church members
Have to have someone with me at all times and people do not want to help
Haven't found one we want to go to.
He has problems being quiet and still.
Head injury
Health problems (10)
Health, transportation
Helping raise grandson-he's too active to take with me.
Her sickness/rainy days
Home bound-Church visit in home
I'm on oxygen and 24 hr home bond
I am ashamed when I have messed up.
I am in pain all of the time, and I cannot walk.
I am not really interested
I am only 9 and have no real interest in attending regularly
I can only go when my mom goes.
I don't always like to be quiet
I go once a week.
I have 2 little boys 3 (not potty trained) and 5. Life will get easier when they're both in school and [NAME] is potty trained!
I have a disabled child which requires mine and my wife's constant attention.
I have a handicap van
I have own bible study, I watch church on TV, Mrs Joyce Myers and others.
I like to sleep.
I need enough staff to take me as well as others who would want to go to church.
I need help.
I need staff assistance and I don't always like to be quiet.
I need staff to go with me.
I spend all the time I want or need.
I try to go visit my mom in the nursing home service since the distance from the car to where the services are held
I would have to pay someone to go with me. Mostly i am in too much pain, but I receive holy communion every Sunday.
Illness-being afraid
Illness/bad weather (3)
Immune system low
Incarcerated
Issues
It's hard for my mom to take me.
It hurts bad when I sit up so long.
It is not a problem. I do attend very regular
Just don't go
Lack of interest (9)
Lazy (2)
Lost interest in church

Low noise tolerance
Medical problems
Medications
Mental behavior.
Mental condition
Mental retardation
Mentally incapable of understanding/too noisy
Mom at work
Mother overwhelmed with responsibility
Must go with a family member.
My autism
My depression and OCD
My disabilities
My disability makes me too exhausted to do anything but work and ADLS.
My headaches.
My minivan is extremely hard for my mom to access easily.
My physical behavior is a distraction to other worshipers.
My preference
Need assistance (4)
Need help getting wheelchair in and out of transportation-customized wheelchair too heavy
Need help; can't walk
Need Personal Attendant to assist
Need repair for various upgrade and moderncation
Needs PCA to drive, take her to church activities
Night services, there is no one to go with me.
No acceptance, negativity, sound sensitivity
No assistance to dress or bring me
No cover when its raining and not enough ramps to enter and exit buildings
No help with wheelchair.
No interpreter, not enough people with my disability
No interpurter for my understanding
No lift in van
No one to take her.
No one to take me.
No one willing to watch or teach my child.
No PCA help on Sundays
No problem, but walking up and down steps
No sign language person
No sign language/asl interpreter
No special needs classes. Need help attending Sunday school.
No support system
No time (2)
No transportation (2)
Not a pledge member
Not able to get around. (2)
Not able to handle cold weather due to excessive pain, not enough driver help
Not always equipped to do so
Not enough children
Not enough help
Not enough trained individuals to work with me at my level.
Not finding the right church I want to join.
Not motivated
Not on time.

Not physically able.
Not religiously active - too much reading involved for my child. It embarrasses him when others realize he is almost 12 and cannot read
Not wanting to get up and get ready
Not well enough
Nothing but weather or illness.
Other obligations.
Overactive
Pain
Parents choose not to attend - can believe and worship God without attending a public place of worship. Churches can be very judgemental toward those who are different.
Parents work frequently
Parking
People don't accept me
People look down on me.
People.
Personal problems
Physical condition
Physical exhaustion
Physical health (3)
Physical problems, illness
Prefer not to be in crowds
Problems
Quad
Recent Involvement
Safety reasons
Schedule (2)
School and actively
School brings me 1 or 2 times a year
Seizures (3)
Setting arrangements are uncomfortable for that length of time, so we usually always worship at home.
She constantly sing (make noise)
She goes to church.
Sickness (3)
Sitting for more than 45 to 1 hour.
So far it's expensive.
Social
Social problems
Some health and disability related
Sometimes there is no one to help me in Sunday School.
Sometimes working on Sunday
Special transportation, staff
Still in pull-ups, messy enter, and difficult to stand still
Study the bible on our own because we do not believe in churches.
Suffering with my back and I can't walk. I need an electric wheelchair
Taking care of sick husband
The inability to sit still
The nature of the illness
Therapy
There is no interpreter or CC.
There is nobody to help me get dressed or take me there.
Time
Time and money
Time needed to attend

Too busy
Too lazy - afraid might get dizzy
Too many sick people with colds and illness
Too much perfume and the church is sprayed for pest
Too much stimulation
Too much trouble getting in and out of the van.
Too much trouble to get in a car
Too tired from walking and standing with everyday living necessities
Transportation
Transportation is difficult for caregiver without lift or full size van
Unable to walk any distance.
Uncomfortable around people.
Unreliable transportation.
Unsafe neighborhood (2)
Usually babysits.
Van with lift (need!)
Walking
We don't attend church in this area.
We go to church and are very involved but still no other young adults like [NAME].
We have an aide to help with child M-F. Child does not attend church very often. It takes 2 people to lift him and no one helps on Sunday.
We need assistance at church for 3 hours of worship
Weather (4)
When my seizures come on.
Work (8)
Worship from home (2)

Table 9. "Other" Problem that Keeps Person from Voting

NO RESPONSE (725)
1st year registered and just didn't this year
Abstract ideas are not easily understood by people with Autism (i.e., elections and religion).
Age (too young) (210)
Age, cognitive limitations
Because of jury duty
Can't comprehend what's going on.
Can't get around.
Can't get to the place
Can't go sometimes
Can't physically.
Can't read (2)
Can't read or comprehend
Can't read or write (2)
Can't read or write because of disability
Can't see or hear well
Can't speak where others can understand him.
Can't understand
Can't vote.
Can't write (2)
Cannot walk, talk or read
Cognitive delays, interdicted

Cognitive disabled
communications, understanding
Condition
Continuing tutorship
Developmental disabilities
Difficulty getting around
Disability doesn't allow me memory on how it's done or who is in office.
Disability (5)
Dishonest politicians that are only in office to help themselves
Disorder
Do not understand (9)
Do not understand the information for the issues
Does not know how
Doesn't understand the concept. Goes with the family to polls. Knows the word vote but does not know why
Don't know who to vote for
Due to cognitive disabilities
Forget
Forgot to register, but i will.
Getting to the place to vote absentee
Going to vote knowing places where to vote.
Handicap
Handicap. Can't talk. Brain didn't develop.
Have not had to go vote
He is a minor.
Head injury-don't know what to do.
Health and no interest in politics
Health.
I'm getting papers so I can vote absentee from home.
I'm not able to
I'm still learning the system.
I am mentally and emotionally a child- MA age 6 or 7
I am not mentally able enough.
I cannot read or write or understand.
I do not understand politics
I don't know how to vote. I can't stand too long.
I need assistance to read.
I vote every election.
In a nursing home
Interdicted (6)
It dont help me!
Just registered
Just turned 18.
Just turned 19.
Keep forgetting to see where we vote at.
Laziness
Limited cognitive ability
Limited understanding. (2)
Mental
Mental disability
mental handicap and bed confined
Mental reasoning, not able
Mental retardation
Mentality

Mentally ill.
Mentally incapable (2)
Mentally retarded
Mentally unaware
Moving (2)
My mom has continuing tutorship
NA
Need a better government
Need to register
Never did
No concept of elections
No electric wheelchair
No help to get there.
No mental ability
No one has taken him to register
No reliable wheelchair.
No understanding.
Nobody do as they say they would
Not 18 years old
Not able
Not able to go
Not able to go vote due to disability
Not always person I want to vote for.
Not aware of political things
Not capable (2)
Not capable of making decisions
Not educated enough.
Not enough time allocated at polls to complete ballot
Not informed
Not knowing what to do
Not knowledgeable enough.
Not mentally capable
Not registered (7)
Not sure who to vote for
Other obligations.
Physical.
Please help me get on Sec. A
Rebecca has cognitive deficits/MR.
Recently registered
Religion
Relocated and need to register again.
Retarded (2)
Severe disability
Sleep late.
Sometimes I just don't go.
Sometimes I would like to stay mutal
The illness
Unable to write.
Usually have problems breathing and walking.
Usually out of town.
Very hard to dress.
Very undecided
Voter registrars would not allow my spouse to enter voting booth with me to press buttons. I have since voted by mail, but I must still apply for each and every election.

Voting machines are hard to access if print is low to the floor with a person on a walker. Cannot stand too long.
Wasn't registered

Table 10. "Other" Service Specified as Needed

NO RESPONSE (967)
24 hour attendant
After school care in middle/junior high schools
Aid
Applied behavior analysis (2)
Assistance in household chore/cooking , bathing and dressing, etc.
Assisted living (Residential)
Assistive devices to help preserve the muscle strength; to me even with a doctors Rx or it costs too much - WC/scooter, extra depth shoes, bars on bottom of shoes
Assistive Technology (2)
Bath tub lift.
Bathroom modifications (2)
Braille, sign language
Caseworker to get thoughtful information to think through a situation (feedback)
Child care /summer camp
Companion when i go out for medical reasons
Computer assistive technology
Computer technology/basic training
Contractor with Medicaid willing to do home renovations to make home handicapp accessible.
Day care or temporary care
Dental Care (7)
Dental or Vision care
Dental work in a hospital
Doctor appointment out of town
Driving
Durable Medical Equipment at home.
Education services on my level
Employment/Training/Education for Employment
Eye and general serivices
Eye care
Eye care and dental care
Family therapy
Financial / future planning
Fitting of braces/legs
Further education.
Help with cost of school tests.
Help with medicine.
Help with school.
Help with the cost of my medications
Hipotherapy
Home Aide Person
Home and community based waiver
Home modification
House cleaning, washing , and ironing
I'd like to see equal pay for equal work.
IEP's in school
Insurance won't pay; medical don't cover

Intense one-on-one LAUASS or similar therapy
Job training (2)
Job training and employment services
Job training from school
Legal
Lift
Lift for van to transport scooter on EC. N/A?
Living skills training -non school environment
Love and compassion
Maid service to help with housework.
Massage therapy and dental services
Meals on wheels.
Medicaid (2)
Medical card/Backtime SSI while I was on chemo to cover all expenses incurred
Medical insurance
Medicare, Medicaid services
Medication card.
Mom needs respite/ PCA
Need a seizure dog
Need deaf/blind communities
Need more and better doctors
Need more in-home services for people to sick to leave home.
Needs OT services to help ADL's
No curfew, needs to be in a better neighborhood.
Not enough PCA hours
NOW waiver
O.D.C.
OB/GYN
Occasional house work.
Orientation/mobility and other visual training
Oxygen
PCA/respite when in the hospital
Personal attendant in home and go places
Personal school aid/teacher aid
Place to go to socialize.
Preschooling and daycare.
Private tutoring
Quicker medical attention
Reading voice machine
Regular health care and check-ups.
Rehab services
Respiratory therapy
Respite care (on waiting list) - needs extra funding
Respite care (6)
School help and bathroom modifications
Self help assistance
Senior Day Center (Activities)
Serious Home Repairs
Social activities w/ other disabled youth, exercise, swimming programs for disabled.
Someone other than my family to check on me, assist me.
Special instruction
Sports-community involvement
Supervised Apartment setting

Support groups and counseling for younger and older siblings
Training
Training to use effectively communication device
Transition to community
Transportation (5)
Tutoring (3)
Vision
Vision glasses
Visual therapy and special instruction
Water therapy, massage therapy
Wheelchair electric and manual
Wife needs help with me because she is sick

Table 11. "Other" Barrier to Living Independently

NO RESPONSE (995)
95% dependent
A lesser plain.
Age (2)
Also have two kids in my life.
Barriers to private homes
Calcaiseu sucks
Can't afford it
Can't see too read about services
Cognitive limitations.
Comatose
Consequence of choices.
Cost for medication
Cost too high
Denied by SS for benefits I'm entitled to.
Dependable employment
Dependable workers
Dependent on mother.
Difficult to make friends
Disability (3)
Don't know what services were available.
Don't know who to ask for help!
Don't understand some forms and can't always fill out
Education parish-wide
Eligibility
Everything is a waiting list. Most services are confusing as to what is required.
Falls through cracks in system. Most services are geared toward MR or physical, not high functioning intelligent people with lack of social perception (but can learn them).
Getting a job.
Getting qualified attendants
Getting reliable help for waiver services
Governmental Bureaucracy, finding good DSP's
Hard or impossible to get on programs which help financially
Hard to get Section 8 when disabled is a child.
Have no barriers.
Health
I am on alternating air pressure mattress. They no longer make this model I have owned it for 10 years, and I need a

new one but the new models cost over 20,000 dollars and Medicare won't pay for it. I have added soars and I'm trying to heal.
I cannot read. I need help to learn.
I do not receive Medicaid
I don't know how to communicate or express myself.
I don't know what is available.
I don't want to go against my families' wishes and I don't know sometimes what I want.
I feel misunderstood
I need a larger home, but it costs too much.
I need a nurse to come in and check my blood.
I need larger home.
I never fall into the right group
I pay court fines and fees, but I want to save money!
Improperly trained PCAs
Interdicted
Just the fact that he can't do anything that a regular kid can do.
Laws and regulations are not followed
Limit on income
Long wait lists
Low wages make dependable help hard to get
Mental health care turned us down when this boy was in a serious crisis.
My aunt works and takes care of me.
My LRS case worker is very disorganized and uncaring.
My specific "mix" of disabilities.
NA
Need 24 hour assistance
Need full medical/nursing care.
Need Medicaid Waiver for PCA
Need personal attendant. Unable to get on list.
Need PT and OT.
Needs help with personal care all day
No central area to find out about services
No cure
No one cares
No SSI or social security benefits
Not capable of being alone
Not enough Braille.
Not enough funding
Not enough information to families who are upper middle class and white.
Not enough personal assistants to do what you would like.
Not enough time. Services are not available at convenient times.
Orthopedic, cognitive
Our area does not have facility that specializes in brain injury
Our caseworker doesn't know of all services we can get where to get them.
Our income affects us from getting the services we need.
Prefer not to have to use provider agencies to receive home care need more in home medical services. Provider agencies make in home staffing more difficult.
Public school system is not helping me reach my potential
Quadraplegic
Reliable PCA Services due to shortage
Scared to be turned down.
Services are not right for my needs to live independently.
Services available in another city

Severe and profound mental retardation.
Severe pain.
Social security
Speech
Summer programs
Temporarily dissatisfied with doctor and therapist
The surgery I need is considered elective.
There is no help at all. I've gone everywhere.
They don't listen
Trained staff
Unable to communicate
Unsatisfied with medicaid
Unsupportive school system (public)
Very low income
Waiting list
When trying to get information, I am not getting any.

Table 12. Responses to “Please share any information you think would help us help people living with disabilities.”

NO RESPONSE (602)
[NAME] as a minor receives our insurance coverage, lives at home, and is in special ed at school. Whenever he is no longer eligible for our insurance, is out of school, and no longer lives at home, this survey have very different answers.
[NAME] currently gets no services because we have been on the waiting list since December of '95 or '96.
[NAME] feels and is alone most of the time. She has no friends and no one to drive her to the movies or for a pizza. There should be a support or peer group so that she is not lonely. She is not accepted by others. Transportation is a problem.
[NAME] has services due to financial assistance from family and friends. Private insurance went up 20% this year. Our medical out of pocket cost is \$17,000 a year. He just got medicaid which is helping a little. PCH paid by children's choice - great help
[NAME] is a 10 almost 11 year old non-verbal autistic child. Maybe an advocate with thorough information of services available both governmental and private would be helpful and greater consideration in terms of requirements for SSI would be helpful
1. More transportation for people who goes to the doctor out of Lafayette. 2. More financial help to families.
1. Change guidelines for SSI and medical card. 2. look at each individual, not place everyone in a certain group
1. Copays- Alot of medical equipment is not approved by insurance. 2. Limited number of contractors that are "approved" to make adaption to the home environment. 3. Finding personal care attendants is very important to helping families.
A lot of these questions do not apply because my son is only 14 years. We have not encountered these situations yet. Thank you.
A monthly check to go to school for the disabled to learn to survive. Would like to get asn education.
A problem we have is respite care because we were told that it is not paid for until he is 3. We do not qualify for SSI or Medical card because of our income. Every child should have fund for future needs.
A program with a very cheerful, devotional and study of Bible should come from church membership - don't have it.
A toll free number where we can talk to someone with our complex problems would be nice.
Access to agencies that could help in housing.
Affordable health insurance for people with disabilities who work; allow them to buy medical coverage - offer eye care and dental care for all people with disabilities not just children under 18 or not just elderly. Apprenticeship job train. and internship
Agencies should try to get people with disabilities to get more involved in community activities and help them get necessary help to live better and feel and act as "normal" as possible.
All buildings should have a ramp-it would help the elderly as well as the disabled.

All doctors in LA should be made to take the Medicaid card. Because you have the card, doesn't mean that you don't need their services. And you shouldn't have to travel to New Orleans or Shreveport to get services. People can't afford to travel all over.
All I hope and pray is that I get some kind of help to help me and my children get to life.
All public places should have accessibility for disabled people. Job training should also be offered.
All the money in the world won't help if the person paid to help doesn't care for the disabled individual. People who assist the disabled should be thoroughly screened to ensure that they will not be abusive or neglectful.
Allowed to work and have income, though eligible for some assistance with attendant care. I'm married, so I don't (I couldn't) rely solely on my income. I have insurance, but still have co-payments and cost sharing. 85% of my income is used for my care.
Allowing those with disabilities to assist and give suggestions when planning or engineering public/private bldgs. Including barriers/challenges facing individuals that W/C bound or use special equip. for mobility. Inadequate handicapped parking spaces
Always remember that there are others in far more need than you.
Any suggestions or options that I am unaware of - please enlighten. Willing to hear from anyone. [Left name and address on survey]
Anybody with a progressive condition cannot predict when they will need assistance, so your form is vital Thank you!
As a mother of a child with disabilities, I feel that they should have more handicap accessible playgrounds and public areas.
As a mother of the individual with schizophrenia, I realized the critical importance of the family support even then we lost our son to undiagnosed heart condition.
As a parent and a caregiver, I have been well served with caring for my child. The medical waiver has been wonderful. My child needs are being met at this time. The ARC has been most helpful with information. Thanks for the tax dollars well spent.
As a professional, widow, mother, I feel there is not enough counseling or help for caretakers in regard to helping find appropriate jobs, when sought; improving the system so that clients and caretakers do not feel that they are second class citizens.
As a relative it has been a constant struggle to get assistance. We are told that he has to be 65 before he can get medicare and he is only 37. He is denied certain care
As an advocate for adults with Asperger's, Autism, Behavior Disorders and ADHD, I find most agencies providing services for persons with these disabilities are not specifically trained and many fail to understand the needs of their clients.
As parent, all answers were made in reference to my 15 year old daughter.
Assistance with home improvements; discounts at stores and utilities bills for handicap; free meds; AC in summer, heat in winter; transportation to medical appointments and nice outings - needed bad in rural areas
At this time SS is denying my claim of benefits and I still have problems with seizures. They are worse and they don't recognize my total disabilities.
At this time we have all the services needed.
Autism has reached epidemic figures; there are many young children with it now. It is a very isolating disorder for the child/adult and parents. It affects the whole family. Symptoms may improve, but the disorder is for life.
Be knowledgeable about their personal disabilities, know that all are different - physical disabilities could lead to mental disabilities, depends on each person. Also they may have other than physical disabilities, like medical; as in diabetes
Being able to get the things needed and not cost them very much if anything. Transportation for them.
Being able to work a few hours, and not worrying about how it will affect your income or the few food stamps you get. I'm still under the doctor's care, but one day I hope I can go back to work for a few hrs.
Better access to available services and equipment funds for assistive equipment for me and my home.
Better health care (cheaper health care where you can afford it)
Better means of transportation
Both my two handicap sons and I are disabled are homeless and living in my truck. I've been to Housing Authority, etc. There's no help there and other places. We continue to get turned away. Please help us!!!
Can't find any help with sign language classes. Can't find any help with buying my daughter a new hearing aid. Can't find any help with paying for her to see an audiologist as regular as possible.
Cannot get cash subsidy. We are trying to get him on SSI not that he is 18 and on the Medicaid card. My husband's insurance won't cover him much longer. Please help!!
Cannot plan or participate in any services when you don't get any. Cannot be independent with dignity when one is

made to feel less they what one is.
Case management has been a good tool in informing and helping me get the services that I need - I had a great case worker in [PLACE]. She really was there for me and made sure that I had the info. I needed to make choices.
Cheap housing is much needed.
Children with disabilities should have some type of programs for the summer while out of school.
College students learning the medical field to practice,learn by 1st hand knowledge to improve help available now.Have an activity place supervised where games could be played and transportation to go there.Need help to dicipline 11yr old ADHD child.
Complete, dependable resource information, readily available and accessible. Very comprehensive as far as who can receive servcies.
Continue advocating for yourself because that will make the difference
Cut down on wait times
Daughter can't get what she needs because of a lack of trust on the help given today. She loves people but affection could and would be taken in the wrong way.
Disabilities just don't like to get two many people I know and don't walk the street corner
Do something instead of just talking about doing something.
Doctors and school should have more information on services and how to get help
Doctors talk with the parent, not the patient, who should be encouraged to cope from childhood so that they can govern their adult life responsibly. Our doctor did not want to fool with medicaid-not enough money. Patient needs psychiatrist.
Doctors would give more referrals for services needed. Medicaid limits choices for services.
Don't be Autistic in Louisiana as there is a dearth of chemical-biological-medical support for this. Most physicians are less than useless in their near criminal lack of understanding and awareness of the latest research and treatment.
Don't stop our edu at CA 22. I had just mastered 4th gr reading skills, 3rd gr math skills and basic comp and 1st gr writing skills. Then, I was forced to grad. I was still learning and acquiring valuable life skills.
Each person is different.We all have different living problems.Some of us do not have a support group or anyone to help because family members refuse to give help.So maybe you can depend on outsiders who may know your personal problem and lend you a hand.
Early intervention for autism is critical in the care of children. Most are not getting diagonised or not receiving enough therapy. If this intense therapy is given the child can have a chance to be functional in society.This costs a lot for the poor!
Easier access to where and what services are available and adequate funding
Educate the community about hearing impaired. Improve our needs in our community but I need to learn how to obtain the information and proceed to help and get our needs eventually! Educate the employers how the hearing impaired can benefit the job.
Education for disabled.
Education system needs improvement and more help with teachers and parents to aid handicapp children
Eliminate the 9000+ waiting list for MR/DD waiver by property funding this service. Increase the pay and give DSP's workers benefits.
Establish and identify programs or partnerships with companies that offer employment for individuals with disabilities.
Every kind of help I need I get from my friends and family. I am also about to have a baby and don't have the money for a doctor.
Every program that we've tried to get has long waiting lists. We want to keep in a/r his fam in a happy environ were he is well-fed, medication on time, stays clean. NOW waiver waiting list - 10 yrs
Everyone needs their own evaluation to determine their needs. A cookie cutter policy will not work each perosn has different needs.
Everything is based on income of the people living in my house and that is not fair. I have toget help from family and friends to meet basic needs and that put me over for some public help.
Extend physical therapy services
Families get penalized for caring for disabled at home versus at facilities.Access to PCA's denied unless disabled qualify for Medicaid,so families spend lifetime saving for disabled individual, the money gets used up on care and it's a constant struggle.
Families Helping Families - was a big help to getting modifications for my dyslexia.
Families Helping Families have been an enormous support!

Families Helping Families provided nearly all the information I needed to advocate for my son. He had one case manager who was helpful in advising me of programs which could benefit him. Information, training and practical advice is most helpful.
Families need lots of support and encouragement and the school system is shortchanging our students with disabilities by not providing the (assistance) software they need to learn such as -The sentence master. Many children can benefit from that.
Federal funding set aside to help families/whole families like my family who have disabilities (mother, father, child are disable). Funding for disable people who are waiting for their income to start.
Few dentists are willing to accept mentally retarded persons as patients. Service is very expensive. Neither Medicare nor Medicaid will help pay for the service. The person for whom their form was filled out needs this service badly.
For disabled people who are homebound, depression begins. Those who don't have family or friends need people to talk to. Visitors to talk to, play cards/games/etc - something to look forward to; you get so bored and lonely, you start hoping you will die.
For people who have disability, it is so hard to get on section8. You can't even get a good income. All I get is a little cheque.
For the government to not cut programs, funds, etc., and for Medicaid to pay bills to doctors without denials the first time.
Funding for speech therapy is necessary. Act 816 passed in August 2003 made it possible to obtain hearing aids for children under 18 years old with insurance. Great Benefit!!!
Funds need to be allocated for personal care attendants for people with disabilities. It is a great strain on some families to provide this care daily.
Garrett receives Children's Choice Waiver, but it does not pay for: communication devices, software, computers, and switches. He is non verbal and needs this type of assistive technology.
General public should be better educated about disabilities that require minimal hours of work and time off for frequent illness in the case of compromised immunity
Get help for the kids while their still in high school. Get ideas of what work is out there and what job training.
Gets \$324 a month and cannot afford medicine. Does not know if wheelchair could be used; losing use of right arm and both legs. Really scared; seems as if no one cares.
Getting help is like pulling teeth. With much begging, has received a PCA for the past 1 1/2 years. Disheartening when minorities get more than the disabled.
Give that person as much Respite care as needed if this person cannot live alone; that leaves the burden on his parents - then what happens when parents can't help him anymore - cannot put that burden on brother and sister
Give these people what they need to cope with their lives.
Grants for wheelchair vans and driving programs for the handicapped. Insurance programs that are realistic.
Hardest part is the fact that health insurance premiums are very high and any services that are based on income do not benefit those whose family income are too high. Why can't those regardless of income get services?
Has been in special education from the 3rd grade thru 8th. Louisiana will not recognize my need for IEP's and modifications.
Have been unable to get (illegible) for son with down syndrome.
Have Medicaid cover dental and vision as well as doctors visits over the age of 20. Also have Medicaid cover dental braces.
Have one place to get help in filing for and filling out all the forms for all services offered. It is very hard to find out all that's available and next to impossible to correctly fill out all the forms. Need a state/federal clearing house.
Having people who are trained in working or helping someone with a disability. She has gone to AARC (month). They complained about her not working (packing bags). She went to AARC about 3 years ago. They complained. It was the same thing.
He doesn't qualify for help bc he is borderline MMR. He never has; because he doesn't comprehend the consequences of his choices he stays in trouble ALL the time.
He needs to learn to drive a car; I don't know how to drive (mother); he has to learn more about how to handle his finances; he works part-time in the cafeteria and the attendance office @ [PLACE] high school; he wants training and experience to be independent
He only gets what he needs. His social life is limited because he hates to leave home and home life is limited because we can't afford things like computers or games etc.
Healthcare is not available for the middle-class working carrying a heavy load. I pay 350. a month while I am stable and healthy with my disability. I would hate to think what my perscriptions would cost if I was ill.

Help develop better funding sources so that people with intensive support needs can have assistance in developig micro-enterprises and have sufficient supported living options including skilled staff on-site and back-up staff.
Help get transportation to training school for young ladies with disabilities, like my girls.
Help me to read more books on my own. Spelling.
Help our helpers, please. Don't make obtaining services so difficult. We're not trying to beat anyone out of money. We really need the services. Thanks for opportunity to share our concerns!
Help them get enough money to be able to get their own vehicle.
Help them to get equipment needed if they can't afford the cost. I fought with Medicaid for 3 years to get a special elevated bed my child needed to keep him from choking and having accidents, which I finally got one from a family in Ohio.
Hire the disabled-even parttime, to give us a purpose in life and fulfillment.
Hold the agencies accountable for the money that they get. DHH should regulate the money. Put the power of decision-making into doctor's hands. Channel the funds to the patients and aides.
Housekeeping, cook, maintanance and information on how to reassure this?
How did ya'll get my address and name?
I'd like to get modifications and other things needed sooner.
I'd like to see someone come up with a new work to describe who we are as a group or individually. Instead of being labled as someone living with a disabilities.
I'm filling this out for my aunt who is cared for by my mother. She was born at a time when training was not available for independence. Finding out about care and training is difficult. We would like to see her have some social activities with others.
I'm in a wheelchair and cannot find a job in the community.
I'm on two waiting lists for services but the time for waiting seems to take forever. That needs to be addressed.
I'm the parent of a 4 yr old and I can only go to school and come home. I wish the state had a place to put kids just on the weekends if the parent has to go out of town.
I'm tired of fighting fo my child's rights and to get help. And when I ask for help, people treat us like trash. People don't understand how much work it takes to keep her home where she belongs.
I also have back problems and sometimes have trouble walking.
I am a foster parent of a child with a behavioral disorder 2001-2002. Because there was no appropriate spec. ed in Orleans Parish for her, she was placed elsewhere.
I am a health care professional who works with children who have disabilities. I believe the most important factor is getting support for the parents and also please don't put a limit on these families' income. Income should be unlimited. Thank you.
I am a mother with a mentally disabled child and I feel that there should be more help to parents in the public school system. You get some services but getting the school to follow them is almost impossible. The school board should work on this.
I am a person living with HIV, I was refused a SSI card and because of that my Medicaid card was taken away. I can't afford any of the medications, nor can I go to a doctor or specialist if any problem occurs.
I am a quadraplegic and I can only get medicare that does not fully pay for my medical needs; even though I am totally unable to hold a job of any kind.
I am a single parent on a single income; everytime I try to meet their needs (financially), I am punished because I work and have insurance (thought that was the responsible thing to do). My child has a dead beat dad. Insurance limits you.
I am homeless because a landlord kept my deposit and rent money 850.00 cash. Never gave me the house. I was made to fight in small claims court to get my money back. My food stamps were taken away because I don't have a house. I'm homeless and hungry.
I am living in a nursing home because I am not elgible for medicaid due to my income.I would like to become medicaid elgible and move home with my wife.
I am not sure what you are able to help with.We purchased a used van and put a not on it. it is not customised for my husband's type of injury. the cost for the one he needs is around \$25000. We need help.
I am on a fixed imcome, and section 8 housing is not available because of a 10 year waiting list.
I am on Hospice, I'm in a wheel chair, on oxygen 24hrs a day, I have 24hr care, vascular heart disease, dibetes, muscle and nerve deteriation, seizers, kidney failure, In Testants, stroke, congestive heart failure.
I am on long waiting list for Independent Living and the Council on Aging cannot answer my questions or help me.
I am pleased with the serviced I get for my daughter, though I think there's a lot of families out there that need these

services and don't know about them.
I am unable to get medicaid because of my income. Need more braille materials.
I am unable to pay for some or most of my medicine. Because all I receive is S.S.□
I am very thankful for Charity Hospital, but their pharmacy has no antibiotics.They have no podiatrist for diabetic feet, no help in getting diabetic shoes, doctors usually change every 3 months. Also, it takes hours and hours of sitting and waiting in ER.
I answered questions for my son. Learning disabilities are our toughest battle. After high school we get left on our own.
I believe people could benefit in the legal advice department and legal aid.
I believe that disabled children who have parents that work are penalized. We do not qualify for medicaid and therefore miss out on a lot of services.
I believe that we as human beings are all created equal and should we have a problem or whatever, society should not hold us back and should allow us to reach our goals, but the system makes it very hard to prosper and our short term seem out of reach.
I can answer these questions "positively" only because I currently earn enough money. Five years ago, you would have gotten very different answers. We need better access to housing, transportation, education, and employment.
I can live own by own, but I can't afford the rent, utility and my medicine. I have a truck I'm trying to fix it but with what I can't because my medicine comes first.
I consider not knowing how to read a "disability". If there are more services in my area on teaching basic reading comprehension it would be nice.
I could use help with household cleaning, picking up meds and little errands, appointments sometimes. I have no way of carrying my electric chair anyplace.
I did a lot of research on my son's disability and got us in a few organizations. Put pamphlets in doctor's offices and government offices. It is up to the parents of young ones and caregivers of older ones to reach out and call the numbers. Thank you.
I did not finish this because I am not disabled. I am raising three children with cystic fibrosis. None of these questions pertain to me, and they are too young to answer them.
I do not know how to get help.Schools offer no help with resources or services. No transportation is available.
I don't perceive myself with disability; rather society has a difficulty embracing the modernity I represent. I'm able to confront any situation, but I refuse to fall victim to the failures of other's projections onto me and certainly not at my expense.
I don't think there is enough research on panic attacks
I feel because I have good parents to take care of me, I am discriminated against. Other people living in group homes or ind. receive more serious services, costing more than I receive, but when I ask for anything I am told my family can take care of it.
I feel privileged to have free swimming available everyday of the week through SLIC in Lake Charles.
I feel the people out there with true disabilities are being cheated from full benefits due to the ones out there that "claim" to be disabled. It makes it harder for people like me.
I filled out this for my son. If you have any questions please give me a call at [number].
I filled this out for Tammy Wescott. I am her father! Tammy has a PCA for 35 hours a week, when they can keep a PCA hired. Tammy was born with CP and has the equivalent of a 3 year old.
I finished school and cannot find a job that I can do. The agency I chose to help has done little to nothing to assist.They only complain about being busy.
I found in past experinces my age was a problem with me getting government assistance. The program would only help people who were older.
I had to fight very hard over the past year to get the additional services necessary for my daughters' growth and for medicaid which was just awarded to us through the community care program.
I have a grandchild living with me and I cannot help her because of my disabilities with my leg, back, shoulder, and stomach. Its hard for me to walk and I have bad nerves and cannot sleep good at night.
I have a mental and behavior disorder that the doctors have not been able to help me with.
I have applied for SSI for my son many times and each time was denied. My child is 13 years old and he has suffered from being deaf in one ear for 11 years. We can't even get a handicap sign near my home. He's handicapped and no one wants to help.
I have been off my meds since 2002 because I can't afford it. I tried medicaid but been turned down and I would like to get back on my meds again.

I have been on Medicaid waiver list since 1999. I have a medicaid card which helps a lot with my medication. I will have a lot more services when I can get medicaid waiver. I don't understand why it takes this long to get waiver services.
I have been trying to get my son a stroller. i can not get the money for it though. My van is too little for his wheel chair, so a stroller would fit better. We need more P.T.
I have been turned down to see a dentist too many times. Please help.
I have disabilities, but I advocate for families who can't get services for the mentally ill, nor can those on medicaid find medicaid primary care physicians or psychologists. There are problems finding structured day programs for the mentally ill and MR.
I have gone through Easter seals for home modifications, the people who did the work tore up our house. Now I'm stuck with a mess and nobody wants to be responsible or fix it. Because med-waiver only fixes it once.
I have limited abilities; I am not qualified to get a job; I do not have transporation, I depend on my mother to furnish a used, rundown trailor to live in. She pays my bills; I receive only a few food stamps. I really need housing assist and financ. Help!
I have my own car but having someone drive me around is hard.I need someone tp assist me in getting dressed, comb my hair. I wear a brace on my left foot, need assistance putting it on.
I have tried for five years to get myson an electric wheel chair. Medicaid won't help. There is no help available for my son. He is totally disabled with Cerebral Palsy.
I have worked in ten long term care facilities as an allied health professional and I have never seen one that provided the quality of care I would want for a family member. There is no substitute for growing up and old in a loving home.
I live in a group home but would like to know what other type of living and job opportunities are available.
I live in a rural area with no public transportation or transportation for persons with disabilities. Transportation has been the main hindrance to my independence. I have trouble getting Medicaid and SSI. With more assistance I could get back to work.
I live in a rural community with no outside support and no activities. In the future, I would consider living in a group home if it would be available in my Parish.
I live in a small community with very limited resources. I would like to have more available resources to meet my needs.
I live on a fixed income with 2 handicapped kids.We are stuck in a trailer that is falling down and need help.We are not aware of services available.Need help feeding kids!
I live with my mother, age 64. She needs more hours of patient assistance. At present, we only are assisted 35 hours per week. We need shower facilities modified to meet my shower/bath needs.
I need charity hospitals as I cannot afford to pay for care
I need home services for a nurse to draw blood to check Diltan and Phenobarbital and Worfarin level. I can't go out and I'm told Home Health cannot come out every three months.
I need to get on Section A. I have my left foot off.
I never heard of a disability such as this one.
I never knew it was so hard for a disabled person to live off little money and get little or no help at all.With housing bills, by the time we pay bills, we have no money to buy personal things. We're robbing peter to pay paul each month.
I received services w/ my local Tribal 121 Program. The United Houma Nation Voc. Rehab. Services helped me w/ a plan to gain employment, receive treatment and research job opps. Evals were conducted and I gained info I needed to explore my options. I am working again.
I see a lot of children at Chilren's Special Health Services who complain about accessibility to state offices.
I take care of my 58-yr-old mentally challenged sister. I have no income and I need to work so I need someone to take care of my sister while I work. She cannot live alone, she needs 24hr care
I take my disability very hard. I have to close my eyes to a lot of things that need to be done myself or afford to get it done. Any help that I am eligible for please send it my way. The thing that keeps me going is that there are people worse than me.
I think having information availble to where you can get services would be a big help.
I think more advocacy is needed to get needs met. There is definitely a transportation problem here as well as high cost for in-home services. There is GREAT need for housing for younger people, with physical disabilities less than 60 yrs. old.
I think people with disabilities should be treated equal, but they don't, people look at you strange.
I think that parents that choose to keep their handicapped kids at home instead of locking them away in a facility where they are laughed at and made fun of should be kept at a financial poverty level so that they recieve the benefits needed.

I think that you have wonderful services, but I just wished you guys could help people like me find a job with the disability that I have. It's hard to find a job that I need. And when I do find a job, it's usually hard to keep because of my disability.
I think the disabled need more jobs so we can pay for medical attention.
I think there should be more services available and newsletters to let you know about it
I traded my medicare insurance for a type of PPO insurance called Oschner Health 65 for better coverage.
I truly hope that changes can be made in the future to allow persons such as Don to have an easier time in achieving the goals that they set forth to accomplish. Getting an education was difficult enough in his high school years.
I want help so I can care for my family like I did before I got hurt. Now my bills are getting so where I can't pay them and I have a wife and two kids. It's hard for me to live with the fact that I am not able to bring in the money I used to.
I want to be able to live with my own daily routine. I need housekeeping help, cooking, and a social life.n Dependable transportation or driver
I wish someone could find a program that I could join because I am 19 years old and weigh 380 or more. It is very hard for me to sleep at night and sometimes I sit up and cry because of my weight. Please Help Me!
I work full-time with the help of my employer, co-workers and family. I have insurance that covers most of my medical expenses, though transportation cost are exorbitant. I don't know of any agency that helps us continue to be productive.
I would appreciate if doctors would make home visits for homebound patients and if medicaid would pay for certain surgeries, such as breast reduction. It is a health hazard and I have a weak heart.
I would like a place where I could socialize with other people with disabilities and have transportation. All I have is my mother.
I would like help given personally whereby not having people given only by lottery (if your name is pulled). It seems like you have to have money to get money. Sometimes it feels that the poor and disabled are not thought about too much in our country.
I would like to get out more but I can't go by myself. I need someone to be w/ me. mother bring to the Dr., but I want to go out some time and be w/ other people my own age. But my mom nup in age and sickly. PC work/don't bring me anywhere.
I would like to have a nurse come and draw my blood for blood work because some days I can hardly walk. There are more people like this
I would like to have more help
I would like to know about any group services for people with severe OCD. Many days I'm depressed and cry all day. I have no insurance.
I would like to know if there can be a support group in Marksville. I'm a 24 year old female living with Bipolar disorder, and would love the help.
I would like to live by my family but I need 24hr care to protect me from harm and to monitor my health needs. There are times when I need 2 staffs depending on my behavioral issues.
I would like to see more funds for teachers to teach kids with autism spectrum.
I would love to have a personal care attendant on a regular basis
If a state medical institution is not disability user friendly then who should be!
If housing needs were based on children w/ disabilities and not whether parent (single parent) is employed or not and if housing was based on greater needs and not a waiting list
If politicians would stop stealing and passing laws to benefit themselves maybe there would be money left over for the ones who really need it.
If possible, to increase the pay for the PCS's.
If someone lives by themselves, but needs to be checked on maybe only once a week, just to see if they are bathing, and if the house is in need of a light housekeeping and most of all, if they are OK where can you get such service?
If there was an organization that helped people buy a home that is on a fixed income.
If you all will help me get some housing voucher. Please, but I thank God for the doctor and my medication that they put me on and the company. Anything you all can help me with I will surely thank you all.
Improve the way information is filtered down to parents of children with disabilities. Education system is not informing parents of rights or resources. My child needs "on task" training devices, but not available or offered as a service parent.
In this state, the child always suffers if the mother has no funds. The stipend that they give to care for someone with a disability is a waiting list of 3-4 years. This is very unfair. Thank you for this survey.
Increase the amount of money that a disabled person can learn per month and still maintain SSDI benefits.

Information should be able to reach people in need. Many programs that are available are very difficult to find.
Informing them about all the places where a Vet can get total eye and teeth problems helped. These were former soldiers who put their life on line for America. Right now America can give them all needed help anywhere on their bodies.
Instead of sending surveys, have community meetings and see what people with disabilities, caretakers have to go through to get assistance. Our problems are too numerous to answer on your questionnaire. None of your questions apply to my grandson.
Institutions and/or organizations or professionals who service those with disabilities are not open on week-ends, holidays or after 5 pm which would be convenient times for appointments. Also, services are very expensive and even with health insurance.
It's hard to get money and design help needed to build a fully accessible home. Denied physical, occupational, and speech therapy because therapist tell us it's not legal to give therapy if no progress occurs, but we get worse faster without therapy.
It's hard to get money and design help needed to build an accessible home. Denied physical, occupational, and speech therapy because therapist tells us it isn't legal to give therapy if no progress is shown, even though get worse faster without therapy.
It's hard when it's more than just yourself in the household...that have a disability...and that person is your child.
It's not the age of a person but the true need of people like me and my wife where our age makes a diff not our needs. Please help us- our house needs fixing, we can't get no help w/ that; I can't walk, my wife try hard, she can't help herself.
It's very hard with my type of disability because you don't know when something might happen. I am very scareddf to go places because of this.
It is difficult to find transportation that accepts just medicaid and it is difficult to get certain treatments that I require without traveling 2 hrs away from home.
It is so sad that people with disabilities have such a hard time getting the help and services they need. I am single, divorced, and live on child support and SSI
It is very hard in this state to get the services. It takes me from two to three years to get the services and the medicaid takes time to prove your eligibility for anything even my son born with a disability and he can be forever and I don't know what.
It isn't fair to expect me or brain injured students to do what "normal" students can do. Passing the LEAP test GEE 21 is impossible for me. And now graduating from high school has become a bureaucratic obstacle for me and others with like disability.
It took over five years to obtain a disability waiver for services for our child. We paid a great deal out of pocket.
It would be a great help if there were adult day cares to tend to disabled people while family members were at work. It would give them anstructive things to do with others for the course of days.
It would be beneficial to have a local central site that help people with al of their needs (residential facilities, home, independent living).
It would be nice if they could give people with multiple sclerosis to get more help with home care. Thanks.
It would be nice to have someone to drive my mom's van so I could go out more often. My mom is the only driver for the van and she is sick sometimes and she has some health problems.
It would help if the information we need to receive aid was more available.
It would helpfult to not have long waiting lists for services. I cannot be left alone because he cannot use arms, hands or legs.
Job Training is very important and independent living. LRS should be the link between the person with a disability and the employer
Just be kind and caring. Always pay attention to physical behavior; that will let you know when they are feeling pain or maybe just somone to talk to. Educate those without disabilities.
Just moved here from Mississippi and is having trouble getting help. Mother and sister go without sometimes so that he can eat.
La has a lot to offer but medicaid makes it hard for the individuals.
LA has poor state services and attitudes for people w/ disabilities. It's really sad because there are so many who want to remain independent but living here makes you more disabled.
Learn of services through social worker at hospital.
Learning more about the disability of people who have them. Like people with polio. Doctors didn't think the polio virus could lay dormant in the person body and become active again like in mine.

Let some of the appointed bureaucrats come down and visit some of the people and family whose life they rule over. Before they make and write the rules they need to see the people they are affecting.
Let them know they are a person too and what happened to them could happen to anyone. Let them see the good in themselves. Let them know there's someone out there that can help them instead of feeling others turn the other way.
Life for the elderly especially the disabled, do much better in their own surrounding (home); instead of putting him/her in a nursing facility. My father (alzheimers) died and his last days were memories of poor care at the nursing home he was in.
Living deaf I don't like and living where I can't see is hard.
Long waits for appointments. Slow paperwork.
Look at the entire picture of the person with disabilities. Do more prevention care (assistive devices)
Louisiana has the worst reputation for treating the disabled. Services are not available and there is no hope in getting them. My son has been on a waiting list in Orleans for 4 years. Public schools are bad and private schools don't treat autism.
Main problem is whti aging and its effects on living independently with a major disability. It gets more difficult each year. Not many realize what special needs are required or how fragile independent living with a disability is. Need more care.
Make available a system of services that is well coordinated with service agencies, education systems, medical services, etc. This should be a well monitored and mandatory system. Nothing is easy for parents of children with disability.
Make it easier for persons like myself to get on Medicaid or some other type of government funded assistance. Help provide with personal transportation. Help with housing repairs needed. Help get prescribed medications for those who cannot afford it.
Make radio announcements or send out fliers.
Making sure enough information is giving to parents when their children who has disabilities reach highschool and about to graduate, know where to begin to help them to live an independent life.
Many people with disabilities could live independently; for some, their disabilities are not "severe enough" and fall through the cracks. My daughter could do more with a little assistance. She can do some things for herself, so she qualifies for zero.
Medicaid needs to assist more with the medical needs of people with permanent disabilities. Fewer restrictions will help assist disabled people to live independently.
Medicaid needs to look at a person's disability when it is a child and not how much income the parents have. Some insurance companies will not accept patients with Marfan's. Others make it impossible to afford.
Medicaid; The last two times I went to the doctor I had to pay (\$9 one time and the whole \$45 the next). If I have to go to the hospital, they probably would not pay enough.
Meeting criteria for services should be made easier and better to understand.
Middle income families have many problems getting help because they make too much , but with a special needs child, its never enough.
Mike wants to be a fireman and to be able to drive.
Misdiagnosed with epicodylitis, I had been out of work 2 yrs; new doc said he felt I had an environmental illness; was refused by W/C doc; I have contacted every source I thought could remotely help or refer me to help; there is room for much improvement
Mom needs to be able to go to Housing Authority nad apply for Section 8 for disabled and not have to wait for lottery of vouchers that are for families. If they had voucher, they would be able to live at poverty and not below.
More at home services needed. Nursing homes cannot care for all individuals who qualify. Individuals who can remain at home would like to do so. The waiver list for personal attendant services is a joke!
More education and training is needed for people with disabilities.
More funding is needed; I have nobody to care for my daughter and respite care is needed. I cannot leave my house alone; I must bring my daughter everywhere I go so I also stay home unless I go to the doctor.
More funds need to be allocated to waiver programs (now and childrens choice). You don't have to be wealthy not to qualify for medicaid! My son is extremely handicapped and needs nursing services, beyond what private insurance will pay for (about 12 hr).
More hours with the consumer to help our needs!
More information needs to be presented to the public through PSA's, internet, etc. The only way you find out about services is by word of mouth. Funds need to be given to a client to use as they wish. Clients need control over funds designated for them.
More medicaid services for children over age 3 with a better rate of reimbursement to providers. Inclusion of sensory

intergration and autism related services to allow for optimal early intervention. More money for services not covered by insurance.
More money needs to be placed into the waiver programs so that people with disabilities can be taken care of at home instead of at nursing homes where they do not receive the care they need. Had to wait 7 years before son was accepted into waiver program.
More money!
More people need to be aware of services and opportunities, more funding is needed for non-profits who assist in outlets for the disabled
More reseach needs to be done on fibromyalgia, bc many people are ignorant - they think its just laziness (look fine, but severe pain on inside); I need to do a MRI and spine Xray, but w/ me being morbid obesity, can't fit in any machine VERY embarrassing.
More transportation needs to be made available
More transportation. I would love to work, but I can't because there is no transp. I like to think I could do some good in the world and just sitting at home makes it hard. But there is a reason for everything and one day I will be able to work.
Mother would love to see services offered more directly and more funds paid to direct care instead of those helping you to get services. See attachment.
My biggest problem with getting a job is when I tell them I have a disability, their interest suddenly dies, and there're reasons I don't qualify for the job suddenly. Unless you can stop this kind of behavior you're not going to help many people.
My child is autistic. He appears normal in public but after watching him for a few minutes you think he's just bad and needs a good spanking. That only makes it worse. More public awareness is needed.
My child is only 8 years old. He will need help in the future.
My daughter has been trying to get the waiver since 5 yrs. There are kids under 15 yrs of age receiving waivers. I have also applied for Section8. I can't get these services. It seems that it is all in whom you know. Children with disability are not treated well.
My daughter is mentally challenged and has physical disabilities. She is not severe enough to qualify for many programs and we are not poor enough to qualify. We seem to be in the middle.
My daughter is only 3 yrs old. All the services we have gotten are great. We've had case managers, therapists, and doctors that have been great.
My disability is very popular. Managers need training on how to learn to deal with employees with mental illnesses.
My experience at charity hospital: doctor prescribed \$200 in medication and I had no money to the RX's.
My experience working with LRS has been very discouraging. Not enough money from job to accomodate home to fit powerchair.
My family takes me to Baylor Childrens Medical in Houston because there are no Rett Sydrome clinics in La.
My friend could be on disability, but he wants to do it on his own. I admire him for that.
My granddaughter's wasn't taught social, living, personal hygiene skills until she was 13, so she is slowly beginning to learn this. I think this is something that should have priority and be taught from childhood.
My husband is internally ill, the doctors said he had about 6 months; medicines, hospitals, and docs are very high, we try not to go to doctors and hosps unless its an emergency, I don't take my meds till I absolutely need it
My problem is with the public school system. They want to reduce the work load on the child instead of giving the child the opportunity to do all of the work with some one-on-one assistance. I would like to see more help for kids with ADHD or ADD.
My sister has a disability. I am her guardian. She is mentally retarded and does not speak. She has lived with our parents since she was born and come to live with me since our parents has passed away.
My son's wish is to find a job and live on his own one day.
My son could live more independently from his familty if he had access to services provided through the home and community based waiver program's Individual and Family support service, and possible supported Independent Living.
My son has a head injury. He cannot do anything for his self. I am his mother. I take care of him. He has lived with me for 27 years now. Some good days some bad days. I have help 5 days a week. I thank God for the help I get.
My son has autism, we have gone to Louisiana Rehab service, did all the tests, evaluations, forms, then they said they did not have the people or money to help for job training, they told ust to see O.C.D.D. services...but we are still without help
My son has Huntington's disease and is dependent on me. He receives respite check once a month which allows me to take care of business.
My son is 5 years old, so I make sure he gets everything he needs.

My son is an 18 year old with psycosis, paranoia, and scizophrenia. He has been in and out of hospitals for the last 4 years.
My son is has downs syndrome. Fortunately we have private inusrance and Medicaid. However, we feel penalized having to pay copayments because we use doctors who do not accept Medicaid. Medicaid should pay this. The NOW has been a godsend.
My son is in need of an FM system for his auditory difficulties, but Medicaid won't pay. This would enable him to return to a school classroom and function at his potential.
My son is unable to hold a job. I am concerned about finding activities he enjoys. He is unable to use his electric wheel chair properly but he has grown out the standard chair. Help.
My son made banner roll in school for the last 2 years and the school paid for the students to go eat. Because he was the only one in a wheelchair he could not go if I couldn't take him.
My son receives Children's Choice. It is so limited that we can't access the \$15,000 allotted for the year. Only pays for diapers.
My son was really too young for most of the questions asked.
Need for supported living for mentally ill individuals. Better services are needed for mentally ill individuals. See comments.
Need help in breathing related activities in reference to his asthmas. Certain foods make him throw up and the medicine makes him gain weight and sometimes slows his thinking.
Need help with prescription drugs, and more services for home care.
Need more advanced services-employment, educational and social.
Need more help for caregivers of persons with disabilities.
Need more help with dealing with children with disabilities. Caregivers need assistance in many areas, special services for middle income families
Need more psych doctors
Need more resources that can be obtained on limited income.
Need should be the first priority. All programs simply put you on a list, which never seem to get any shorter - should 1st send someone to evaluate the person in need. I have been on the list of N.O.W. since May of 1996 - no closer to approval
Need to increase the amount PCA's are paid through children's choice waiver program so more pca's will be available to work or more incentive for PCA's to remain in their job field.
Need transportation service, public transportation can't take you everywhere you need to go. I'm still trying to get lift line service, but it is very strict.
Needs help to be on waiver but has been cut off by occd.
Needs to be on disability
Needs to live in a facility that can provide the one-on-one supervision that is required with no roommate for safety purposes because of condition.
Needs transportation and "in home" care very badly. Was turned down for Disability Waiver because income slightly exceeded the allowable amount.
No one cares enough to help no doctor, agencies or anyone.
Normal people get to make real choices and then adjust them if they don't workout. Why can't we?
Not enough scientific data is shared with the public. It seems that the only data we get is when drug companies advertise their products.
OCDD - very slow in processing request for assistance. All other sources of assistance depend on OCDD evaluation. OCDD does not seem to realize the present need of client to be a little independent.
Once it is known that family has income, it is assumed that services will always be available. Once I reached adulthood services and information stopped. I found co workers and minorities had information about services I might need. This is not racial.
One agency to direct you to the correct service you need, or to explain the types of services available.
One leg is four times the size of the other leg. It's hard to walk a good distance. Can't afford a scooter chair. I feel that our medicaid card should pay for our medicare but it doesn't.
Open more areas where people with disability can work while their family is at work. Or pay the family members so that they can stay home and take care of them. Some disable people do not want others in their home. They do have their own rights.
Open up more slots.

Our biggest problem has been the poor quality of his education system here. It's gotten worse for our son, not better. There is no suitable place for him to transition to when he turns 21 1/2. He will have to stay home w/ us. We wish the community would offer far more.
Our family has two children with disabilities, and we're unable to give them the best care. We've placed them in residential care; one is in training school, other is at LA Special Ed. Center. We would like to have our son back home, but need assistance.
Our parish didn't provide the services under Bulletin 1903. Ignorance isn't LA's problem, it's presumed knowledge! Prevent it from because a disability earlier in school
Our son is currently an inmate in the Calcasieu Correctional charged with simple burglary of a pharmacy. He was on a structured plan with regular drug testing, trackers program, and mental healthcare; all was slowly taken away and then he was arrested.
Our son lives with us at the present time. He will be graduating May 2004. Our journey is just beginning.
Our son needs afterschool care and summer care. The daycares say he is too old to go and during the summer they want \$100.00 per week. We make "too much money" for SSI/Disability and the State doesn't have funds. You can't help us!
Parking for the handicapped needs to be 'overhauled'. Enforcement of existing laws is non-existent, or apathetic, at best. Businesses maintain the bare minimum space required by law. Is it a lot asking for adequate parking to remain independent?
PCA case manager assisted me with the completion of form.
PCAs; Jobs; Accessible buildings/bathrooms in workplace.
People are afraid to talk about their needs. Let them know that you care about them. As a person we are all important, we all count.
People need help with their medicines and transportation. Ones on medicare cannot afford to go to the dr for the deductibles on SSI Disability.
People need to give people with disabilities more chances to try to work and not make it so hard and frustrating to find a job. It's also makes you have less confidence in yourself.
People such as I with deisability can't get Medicare or Medicaid do to getting married. But before I got married I was receiving both, but after I married they took me off.
People that make braces be more understanding doctors who specialize in post polio lower drug (prescription) prices
People w/ disabilities need meaningful social programs. They're often isolated at home w/ relatives as their only hope to take them to movies or comm events. Have programs where the disabled can meet, work on projects together, have some kind of social life.
People who have disabilities very often have no one to help them get the services and treatment they need.
People who help me are underpaid making around the clock help unreliable. I'm supposed to be able to trust them with making major decisions that affect me.
People who live out of city limited, don't have public trans; there is lack of speech therapist and Adult Day Care for disabled in our area; S/IC in L.C. has helped us a lot.
People with a disability like mine need approval to receive two pairs of bifocals per year (every six months) and regular checkups at eye doctor. Sometimes I have problems with Medicare paying and I don't know why.
People with a disability should have the right to receive funds from anyone to help their situation and be able to reimburse the lender when funds come available.
People with disabilities need to have more money to live on. I get \$661.00 and after I pay my bills, there's nothing left. Also, recreational programs, plays, trips, sporting events, etc, would be beneficial.
People with disabilities do not know what services are available to them. I would like to recieve informaiton about services and state programs that I am eligible for.
People with disabilities have a hard time getting services and alot of time are overlooked. Agencies that are supposed to help are not very caring. These jobs should be given to parents or relatives of handicapped children/adults.
People with disabilities need more and better accessible facilities in the community
People with disabilities need more help with paperwork.
People with disabilities need to have a choice in making decisions for their own needs of their disability, if they are in sound mind.
People with my type of disabilities need more comprehensive services to live in the community. I would need 24 hr trained staff, nursing care (daily), specialized transportation, bathing supporters, special lift, bed, etc.
Perhaps a center where I can take my son for socialization in my presence and or assistance will help.
Personal Care Attendant and home nursing services are extremely difficult to obtain. I know someone with terminal cancer who has to be on a waiting list for services w/ undetermined wait time.

Personal care attendant/Services to help caregivers who want to keep their child/love one at home and can't afford to hire help.
Persons with life long disabilities NEED help. The help is expensive and medical insurance doesn't cover it. Need van lifts, BR modifications, etc. and the waiver lists are impossible. I just want our lives to be easier and more accessible.
Persons with my illness, including children, do not get enough of the in-home services they need such as home schooling, home computer training, home medical and/or mental health services, and PCA's. Providers are incompetent.
Persons with permanent, life long disabilities NEED help. The help needed is expensive and medical insurance does not cover - i.e. van lift, BR modifications, wheel chair improvement. So those who have private insurance cannot get above needed services. □
Please continue to help with free doctors and medication for the elderly
Please do something to help the agencies in the long absences of workers. I lost a worker Jan.4 and Feb. 8 now, and I still have no replacement.
Public school system needs more teachers who are able to help students with dyslexia and ADD/ADHD. Most teachers think I am lazy or do not want to do my work and do not want to deal with me. Some teachers do not think students have these disabilities.
Public schools want to label kids with ADD and ADHD as being slow learners or mentally retarded, but they're not. They may have a hard time but most are very smart. My child will probably fail this year because of how overwhelmed she gets with LEAP test.
Put all services and providers in one location. Its too much going from one agency to another because you keep getting referred all over the place.
Relief for caregivers
Resources and support must follow the patient to their highest level of functioning. In Louisiana there's a great need for well trained professionals and para professionals to treat and rehabilitate persons with serious mental illness.
Rural communities do not have the money or expertise to provide adequate educational services. It would also help if there were a complete database of the type of services available.
Schools, especially communication with the children. Sign language - more speech therapy. They can be taught. Teachers have to have patience and love and most of all a heart. Understand a parent been w/ a child from day one. Stop, listen, and learn.
Seems to be a problem with funding PCA/respite hours overnight in the hospital. Please keep communication clear between state and local agencies (suppliers of services).
Service is too hard to get.
Services are very bad. Something needs to be done.
She and the people she works with at the shelter are paid poorly for their work; they should be paid more. They work 8 hour days and bring home \$36-46 per week. This is very disappointing for them.
She has a good life because of how fortunate we are that both her father and I have good jobs and devote ourselves to make sure that her life is as normal as possible.
She has been on the MRDD waiting list since 1996. She received the elderly/disabled waiver for 20 hours a week. She died waiting for the MRDD waiver.
She would like to be home. She was home for 13 years. She became very aggressive with younger siblings and all my time was consumed taking care of her needs.
Some businesses don't have access to get in. Need enough pay and benefits for PCAs because good ones are hard to come by
Some of the questions I did not check because I am not able to work anymore. I had to change doctors two times before my disability was completed. I was having so much pain.
Some retail stores doors are too heavy to open. The stores that have electric chairs are in so bad condition because of misuse. Never enough parking places for handicapped.
Someone should tell my mom and me about help. We have tried for some time but still no help.
Special treatment for the disabled on the job.
State should provide more assistance for the handicap
Stiffer fines on college campuses for persons illegally parking in handicap spaces; more van-accessible handicap spaces to accommodate the space required for a wheelchair ramp/lift; cups/lids should be placed lower in fastfood courts (LSU union)
Stop giving everyone with a toothache a handicap sticker, so the whole family uses it. Parking at hospitals and doctors are impossible and this keeps me from my appointments.
Students with disabilities need the opportunity to be involved with extracurricular activities at school particularly in

high school so they can have a "normal" high school experience.
Supply more money
Support groups help (Acadiana Autism Society; Familis Helping Families)! We like that some services can be shared. Our service provider has been very informative about service options.
Survey did not seem to apply to those living in group homes
Survey not appropriate for a child
Teach them how to find the resources they need. I've gotten a lot of help from families helping families. They taught me a lot.
Teachers must be trained to teach kids with autism. Social and religious groups training on their level would be helpful. I would love to see special masses on CCD prep with proper accomadations for those not capable of getting a diploma.
Thank you for doing this survey. People with disabilities need more sources to assist with our needs.
Thank you for the opportunity to share with you. I have lived many years quite successfully with disability. College was partially paid for by LRS (Voc. Rehab in the 50's and 60's). With an education many doors were opened.
Thank you for your time and concern.
Thanks to Families Helping Families. Was in a dark hole. Ask for people not to leave her. Some people need equipment at home to exercise. Always have someone you can call when you need help
The biggest concern is low self esteem.
The biggest problem I have is financial. Our child was disqualified for SSI and Medicaid. The income guidelines are far too low.
The biggest problem is trying to get medicaid/medicare to pay for hospitalization for dental work. My son will not allow any dentist to work on his teeth in the dentist office. He must be hospitalized for this, which Medicaid should pay for.
The biggest problem we face is that my child is either too handicapped for some porgram or not handicap enough from some program.
The care and access to Medicaid and therapy applied to all 5 of our adopted children with special needs.
The cost of suppliment is extreme. Takes 45% of my social security check.
The disorder I have is extremely rare, even NORD has not heard of it. There has been less than 50 cases worldwide and it does not effect people the same way. I don't fall under any one category and fall between the cracks when it comes to services.
The earlier treatment begins the better. The school system was no help whatsoever. The state needs ABA which has a 50% recovery rate. LA needs to be more progressive. We have been very discriminated against.
The hours of care that people with my disability receive are inadequate.
The main problem I have run into is thransportation. It is very hard to secure financing and I have found no agency to help with this.
The Medicaid waiver is what makes it possible to answer all these questions positively. It needs to be available to all people who need it.
The medication costs too much money. He is getting to where it is hard for him to walk. Would like to have scooter but cost too much money.
The PCAs should be paid more. We live so far out of town taht we can't keep anyone. There has been three people started and quit in a week after they started. The job is not hard. But no one wants to come out on these bad roads for \$5.50 an hour.
The place that we live don't have the \$ in order to get the things we need like a washer, dryer, etc.
The process of getting assistance from the staste is difficult. The waiting lists are long. If individuals do not have family support - it would be very difficult raising a child with a disability.
The public needs to be more educated about disabilities.
The school system has their own idea how to teach me. My mom got help from Laf. arc. A person comes to my home monday to friday help me read, count money. I'm 17 years old and need friends besides my family.
The school system in [PARISH] doesn't offer programs for me. We need some type of program so I can stay in school. Could use other programs to help figure out where I belong.
The schools need to offer more therapy than once a month and more one or one time with each child.
The shortage of reliable staff is a problem and has a definite impact on person's living on their own. Incentives of higher pay and benefits would encourage more persons to seek a career in PCA. Need more waiver slots for people to live in the community.
The social security system is cutting people off who need the income to live on if the disabled persons gets put out on

the streets with kids, the system doesn't care. As long as they don't get hurt. It's hard to find disabled person a job like myself.
The state does not consider Dyslexia with behavioural problems a form of disability in order to make payments for SSI. In my high school, they only believe you should get help with Dyslexia only if you ask for it, they do not volunteer it.
The state has decided that orthopedic surgery is elective and has or will not do any surgeries unless it is trauma or life-threatening. I could walk and work again with surgery. Now I have to stay at home and live in poverty.
The state needs to raise the SSI and Disability Income enlarging small houses into bigger ones for the handicapped. A special place is needed for handicapped to have fun, there is none in LA. Need teachers who cope with handicapped conditions.
The waiver program should be on an as needed basis. We waited 18 years on a list. When my name came up I was happy living in a group home. Six months after we turned the waiver down I was unhappy and had to go back to the bottom of the list.
There's not enough information about the services available
There are no benefits/services available for single clients with no children when a disability disease such as crohns. No insurance co. to insure because existing conditions. No SSI \$ because disease allows person to work sometimes.
There are no dental services for adults with disabilities. I enrolled in LSU Donated Dental Service Program 4-8-02 and have not received a call and phone number won't allow a message.
There are no services here in the rural area for a Mother's Day out, or any time out. We can't afford private sitting, we are paying for a van with a wheelchair lift.
There are no services in my parish of any kind of speech, O.C. Therapy, Camps are in another Parish and are very expensive.
There are not enough attendants accessible to me that are familiar with assisting with the bowel program.
There are resources to assist my needs but there are long waiting lists. I am highly independent however I need help in paying bills and preparing proper meals. System of care should be equal.
There are very few doctors who know anything about post polio syndrome, also known as the late effects of polio.
There do not seem to be any coordinated services. Waiting lists for help are very long and funding is pitifully low.
There is absolutely no effort or help provided to parents and children who suffer from bipolar disorder. It is not same as ADHD or autism and yet we are lumped into those categories. We need more real help.
There is definitely a need for Louisiana to have a home which caters only to people with prader-willi syndrome. The uniqueness of this disability makes this imperative.
There is little awareness of asperger's syndrome and many misconceptions about bipolar. People either don't know what it means or think we're crazy. My son needs services but the state says we make too much money although we get less than half our income
There is no priority in Louisiana for persons with disabilities look at West VA. or Georgia. They have programs to help pay for insurance, pca's respite Medicaid for ALL people with disabilities. Louisiana makes it harder.
There is still a big misconception about blindness. My son is a sixteen year old who is very intelligent yet many people perceive him as not being able to do things because he is blind. Please help to raise public awareness about blindness!
There isn't enough help allotted for my disability. I need more PCA hours allotted.
There isn't enough info out there for people to know where to get help
There needs to be more truly handicapped apartments. Apartments with wheelchair accessible showers and lower cabinets.
There should be a public agency that would give vouchers to low-income or disabled people for a decent car or truck in the same way they get help with section 8 housing.
There should be an agency that people with disabilities can go to get help with medicine and utilities. It is the two most important issues.
There should be easier for deaf people like me to be able to get all equal fair.
There should be more available housing opportunities for families caring for children with disabilities. My family is very limited in resources because the mother must stay home to care for handicapped child. No child care assistance opportunities for
There should be more funds toward getting help for those who are disabled and more places of businesses such as restaurants and stores should be accessible for handicapped people.
There should be more information for people with disabilities so that one can get help oneself instead of depending on others. I have the experience that the agencies are so busy that your needs fall on deaf ears. Nobody seems to care.
There should be more training for teachers and aids to be able to help our kids with disabilities. There are no group events or functions for us to go to in our area. When we get them they end up shutting down because of funds.

These services show has more people to help disabilities it a lot patience understand, love, faith, hope, pray. Medicare card should be givin to people in there 46-65. It a lot people don't have money transportation to get Dr. They are on a low income.
They need help with their medicines. It's too high.
They need to start off with the basics of life if their brain can't remember, not ask them to sa or do something and when they can't, immediately, they giveup or say they'll never recover. Brain disabilities take along time to recover.
They should be informed of help available. If you have any income you can't get help-but you don't have enough to pay for it. I have had kidney surgery and unable to fill this. I think assistance is unfair in LA or I don't know where to get it.
This 14 year old boy lives with his parents. He is autistic and right now he is currently in school. Our goal for him is that someday he will be able to work and live in an ind. group home. He will need job training then community services.
This is a wonderful child who has improved significantly in his home. Residential treatment would be DETRIMENTAL for his development at this time.
To learn how to be on my own and to get my GED so I can go to college to do computers and read and spell better. To learn lots more.
To recognize this, our needs, as normal people, who can help ourselves as well as recieve help from others, and to keep us from embarrassment.
Transportation is so important. People live outside the city in the county.
Trouble with payment on some medical services - her medical card has not paid, so seeing these specialists are becoming a problem. Some services not covered by private insurance, such as her braces for her feet and some dental problems.
Twice I was told by Doctors that I needed to go into a nursing home and twice my wife took me home and nursed me back to wheelchair transfers. She needs help now because she's sick and who will care for me?
Unable to get Medicaid due to my income.
Unable to receive Medicaid because of my income.
Waiting lists are horrendous for assisted living. He's frustrated because of the quote "wants to live a decent life in God's will."
We are an extreme case of things working for us, because I have knowledge of services. If I should die where would my child be if we don't advocate for more services, transportation, and money to assist adults with disabilities to have a life!
We are new to learning of services and help, but the child does not recieve medicare or social security. He attends speech now only once a month which is not enough to help him.He's in special ed in school.
We could use more public transportation and medicaid
We do need more transportation to get to and from places. Are being told one can get these services.
We get some outside help for a few hrs/week. State-run org - It's almost imposs to find honest and reliable help for the pay 5.50/hr. I interviewed at least 20 people, no one wanted to work for 5.50/hr
We have another son age 18-sever OCD-had to drop out of public school at age 15. Unable to get services from vocational rehab because dropout unable to get help through JPSS. Need Help
We have found w/ a child the waiting of transition from early intervention to OCDD waiver programs is very long and costly.
We have very little income so we are not able to do any remodeling in the place we live in such as wider doors, bathrooms, and closets. Also need better public transportation.
We live in a rural area and have problems getting OT, PT and speech specialist to come out to meet us. We currently drive two and a half hrs round trip for services. Other rural areas need help too.
We need more access to get wheelchair lift for van: paid for by medicaid. Also need help getting respite care.
We need more medicaid waiver slots for the "now" program that provide PCA/respite care for clients so they may live independently.
We need more primary care physicians and specialist to take medicaid!
We need personal care attendant services available when needed. Our rights as mental patients should be same respected as senior citizens.
We need the correct equipment to make our home and van handicapp equipped.
We need to have more info about SLE lumps, low income housing, and counselors for us to talk to about the way we feel at times.Also activities to do on our good days.
We were never aware of any services except SSI and were always told he didn't qualify because we made too much

money. It would be nice for a place for him to go to in the summer and school holidays for respite care so I could work.
Well I have a disability, I don't get medicaid.
What I find is frustrating is the state agencies notify us that services or special funding is available to help assist me, but when my advocate tries to access these services I still run into a brick wall because rules are not constant and are confusing.
What will be nice to have when a young adult reaches the age of 21, they will have a doctor for them that takes medicaid.
Wheelchairs should be designed to fit each person's specific needs.
When applying for a job, these people don't like to hire people with disabilities. In some cases the situation should be reversed, so they can feel what it's like. How they make you feel, we don't want pity. We just want to work and make a living.
While attending school, and having an IEP, I felt that the teachers should follow the guidelines set up on the IEP. I think if the IEP's were administered better he would not be as far behind as he is now.
Why did it take so long for my child to get help? Why did my child get lost in the system?
Why must we live at poverty level to qualify for help?
Will not be covered on parents' insurance once a certain age is reached. Will not be able to get own insurance because of diabetes (Type 1, since age 2). Autism disorder complicates self-help skills.
Will probably need help in the near future for wives progressing alzheimers.
Would like to have information on receiving Section 8.
You should not have to be poor to get services. Just because you work or your parents do, that does not mean that you can afford services or that you can get insurance. People with disabilities in the middle class suffer the most.
Young adults with mild PDD or cognitive disorders are employable and could live fairly independently-there is a shortage of job assistance, housing, and living skills training.